



Treating ME/CFS

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Berlin, 12 May 2023



Treating ME/CFS

- Recent guidelines, what do they tell us?
- Treatment based on cause/ pathophysiology
- Multi-disciplinary approach to management (BC example)
- Can we make it work for patients?

Recent Guidelines on ME/CFS



CONSENSUS RECOMMENDATIONS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management

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Opinion

European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (EUROMENE): Expert Consensus on the Diagnosis, Service Provision, and Care of People with ME/CFS in Europe

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NICE guideline on diagnosis and management of ME/CFS
<https://www.nice.org.uk/guidance/ng206>

NICE 2021: Selected recommendations



- **Existing evidence for interventions limited and low/ very low quality**
 - Energy management: main strategy for symptom management
- **Do not offer:**
 - CBT as a cure for ME/CFS (*only offer to support people who live with ME/CFS*)
 - Any therapy based on physical activity or exercise as a cure for ME/CFS
 - The Lightning Process, or therapies based on it, to people with ME/CFS
 - Any medicines or supplements to cure ME/CFS (advice on symptom management)

Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management

NICE guideline [NG206] Published: 29 October 2021 [/guidance/ng206](https://www.nice.org.uk/guidance/ng206)

EUROMENE Expert Consensus treatment goals

“To treat the most distressing symptoms (sleep disturbance, pain, orthostatic intolerance, or others) and empower the patients to be in control of symptoms and the disease by encouraging them to trust their own experiences and enhance their awareness of the activities and environments in which they can cope without exacerbating symptoms, and “pace” themselves accordingly.”



Support measures

- “Pacing” and activity management to work with the “energy envelope”
- Supporting therapies that could help with coping and adapting to changes in life due to symptoms, within the “energy envelope”, and counselling or psychotherapy
- Occupational therapy provided by professionals with experience in ME/CFS patients
- Social workers who could help with social welfare
- Educational needs: welfare and educational sectors should be involved in the planning and care for affected patients, particularly children, adolescents, and young adults
- Range of non-pharmacological approaches



Examples of pharmacological approaches

Pain

- Paracetamol
- NSAID (for short periods, e.g. up to 7 days)
- Gabapentin or pregabalin
- Tricyclics, e.g. amitriptyline
- Low dose naltrexone
- Duloxetine
- Venlafaxine

Autonomic dysfunction

- Fludrocortisone
- SSRI
- Midodrine
- Ivabradine
- Pyridostigmine

Sleep

- Tricyclics, e.g., amitriptyline
- Trazodone
- Melatonin
- Doxepin low dose
- Diphenhydramine
- Promethazine
- Benzodiazepines and Z-drugs (for short periods only)

Anti-allergic/anti-inflammatory

- Antihistamines, e.g., fexofenadine or famotidine
- Sodium cromoglicate



Targeting the pathophysiology (examples)

1. *Dysautonomia*
2. *Neuro-inflammation*
3. *Immune disturbance, infection, inflammation, auto-immunity, dysoxia, endothelial dysfunction, metabolic abnormalities...*

Pathophysiology and treatment of POTS

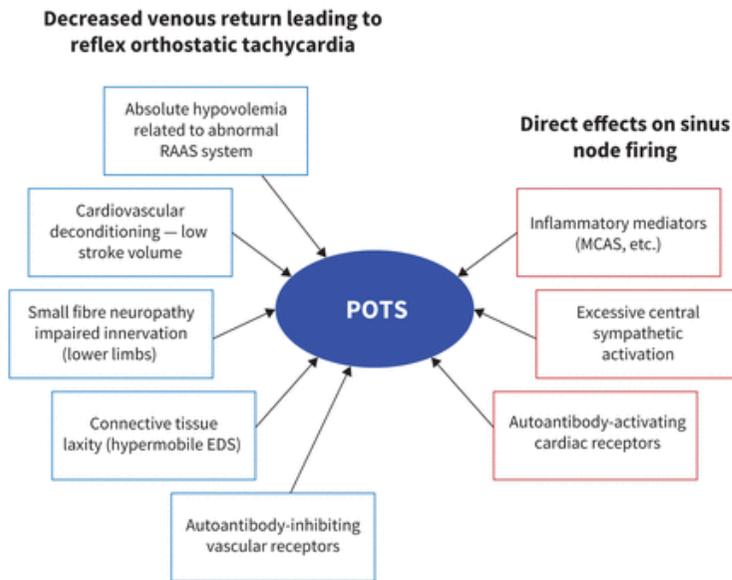


Table 2: Pharmacological treatments for postural orthostatic tachycardia syndrome

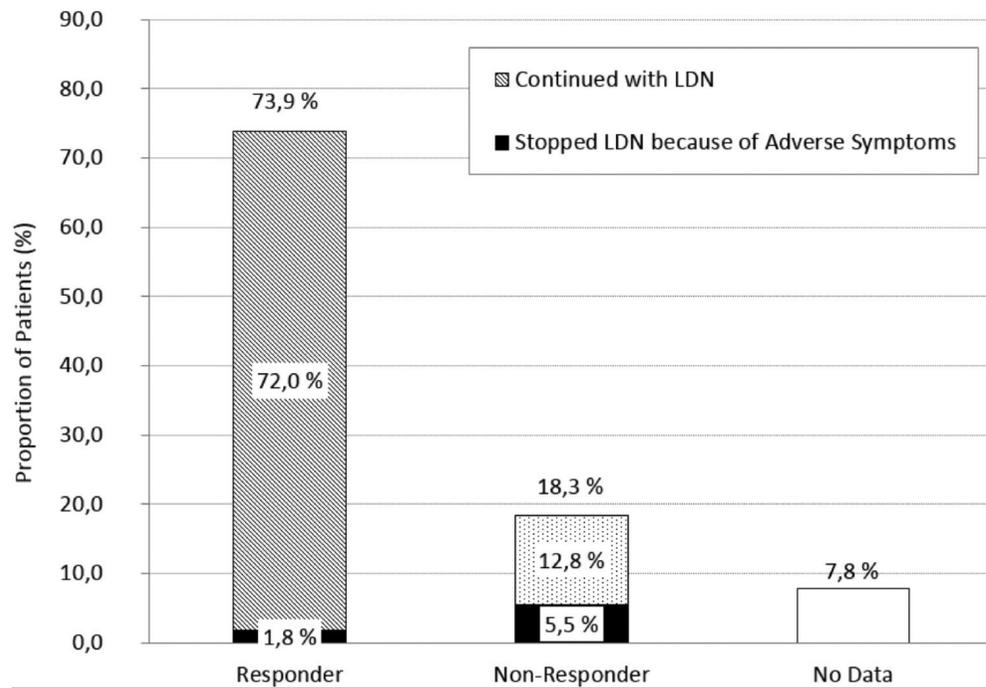
Drug	Dosing	Quality of evidence*	Adverse effects	Other considerations
Heart rate inhibitors				
Propranolol	10–20 mg orally up to 4 times daily	Moderate	Hypotension, bradycardia, bronchospasm	Can worsen asthma
Ivabradine	2.5–7.5 mg orally twice daily	Moderate	Visual disturbances, bradycardia	Expensive
Pyridostigmine	30–60 mg orally up to 3 times daily	Low	Increased gastric motility and cramping	
Vasoconstrictors				
Midodrine	2.5–15 mg orally 3 times daily	Moderate	Headache, scalp tingling, supine hypertension	Avoid within 4 hr of bedtime to avoid supine hypertension
Sympatholytic drugs				
Methyldopa	125–250 mg orally twice daily	Low	Hypotension, fatigue, brain fog	Start with a low dose
Clonidine	0.1–0.2 mg orally 2–3 times daily or long-acting patch	Low	Hypotension, fatigue, brain fog	Start with a low dose; withdrawal can lead to rebound tachycardia and hypertension
Blood volume expanders				
Fludrocortisone	0.1 to 0.2 mg orally per day	Low	Hypokalemia, edema, headache	Serum potassium should be monitored
Desmopressin	0.1 to 0.2 mg orally per day, as needed	Low	Hyponatremia, edema	Serum sodium should be monitored if used chronically

Raj et al, 2022

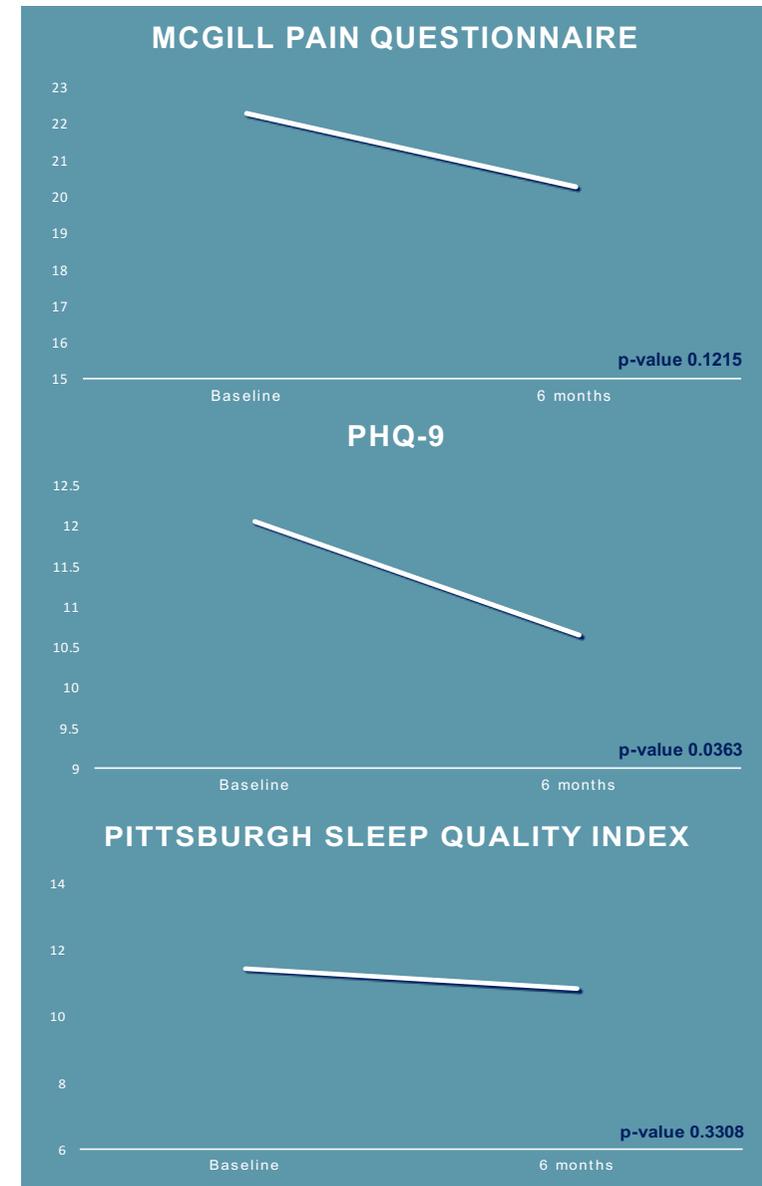
LDN response in ME/CFS case studies

Opioid antagonist
LDN (~4,5 mg)

- 1) improve endogenous endorphin function (upregulate opioid signaling)
- 2) neuroprotective and anti-inflammatory effects by suppressing microglia activation (immune-modulator)



Pollo et al, 2019



McKay et al, 2020

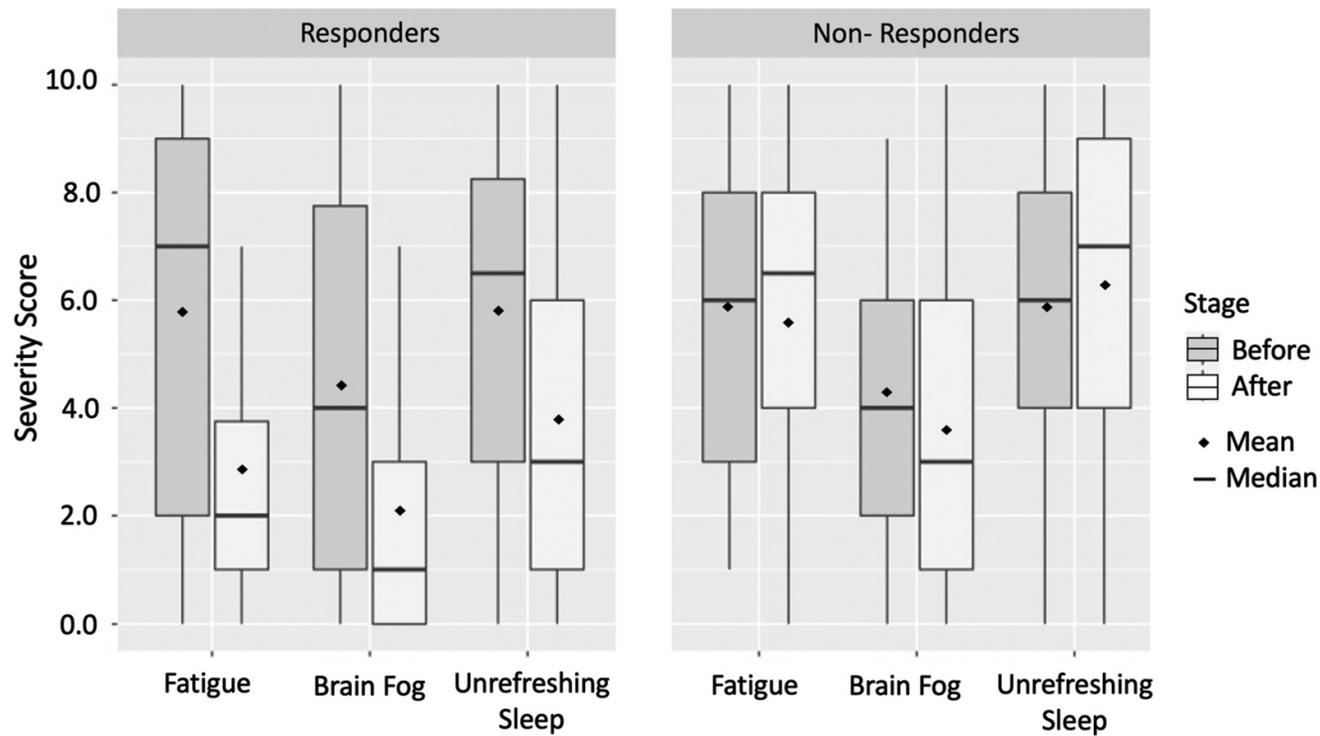
Low-dose Aripiprazole retrospective chart review

n=101; Responders=74%

Aripiprazole (0.25 to 2 mg/day)

Dopamine D2 receptor agonists (dopamine-modulating drug)

Mediate neuroinflammation and microglial activation



Integrated Program example: the Canadian Provincial Program for ME/CFS and other CCDs



BC WOMEN'S
HOSPITAL+
HEALTH CENTRE



CCDP Model of Care

IP Groups

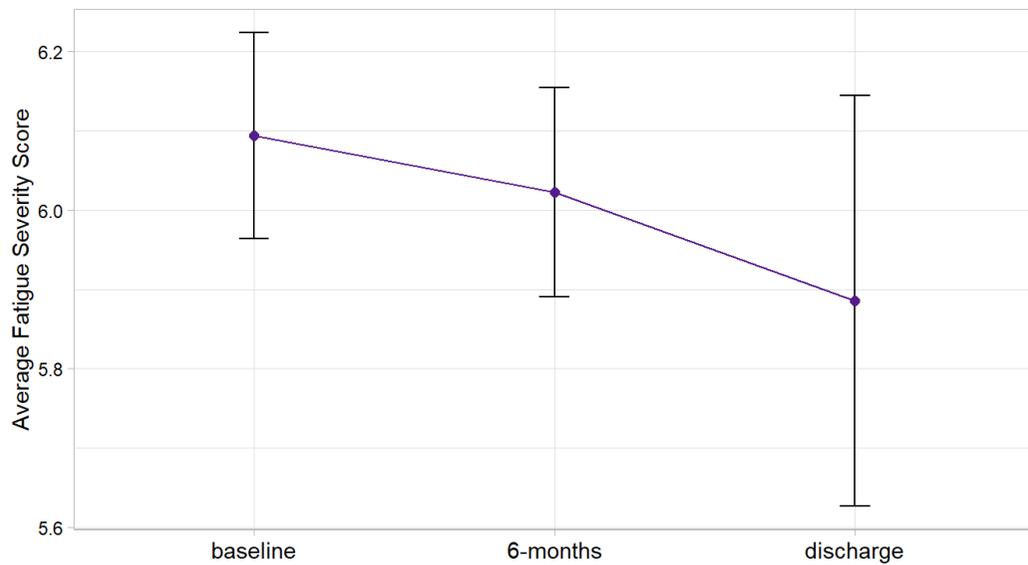
- Pacing
- Mindfulness
- Pain management
- Cognitive
- Beneath the Surface
- Acupressure
- Naturopathic

Individualized care

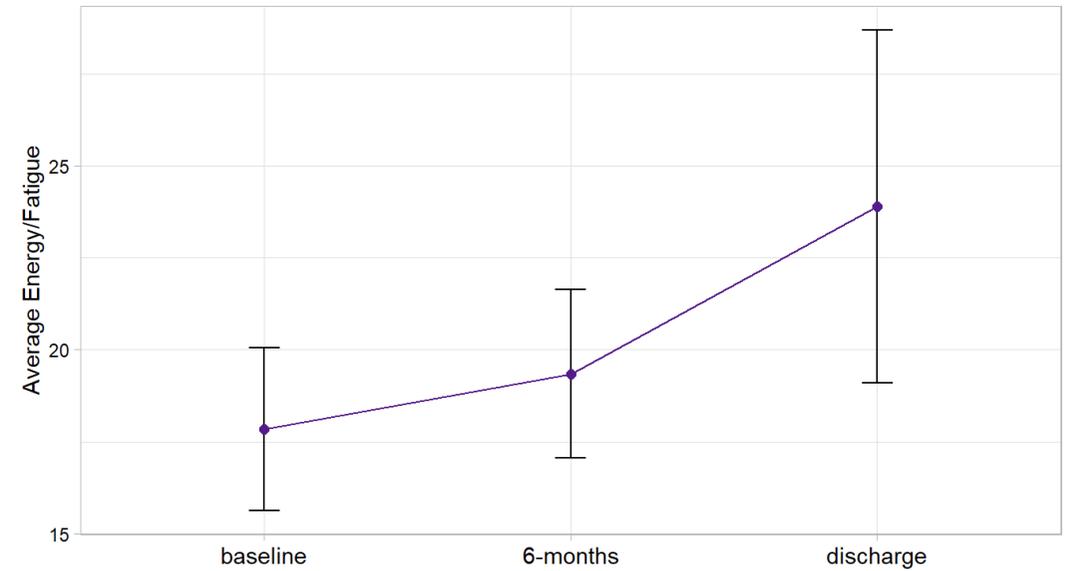
- Medical assessment for confirmation of diagnosis and treatment plan
- Medical follow-ups
- Pharmacist appointment*
- Allied health professional apptment*

CCDP Data Registry selected outcomes

Fatigue severity score*



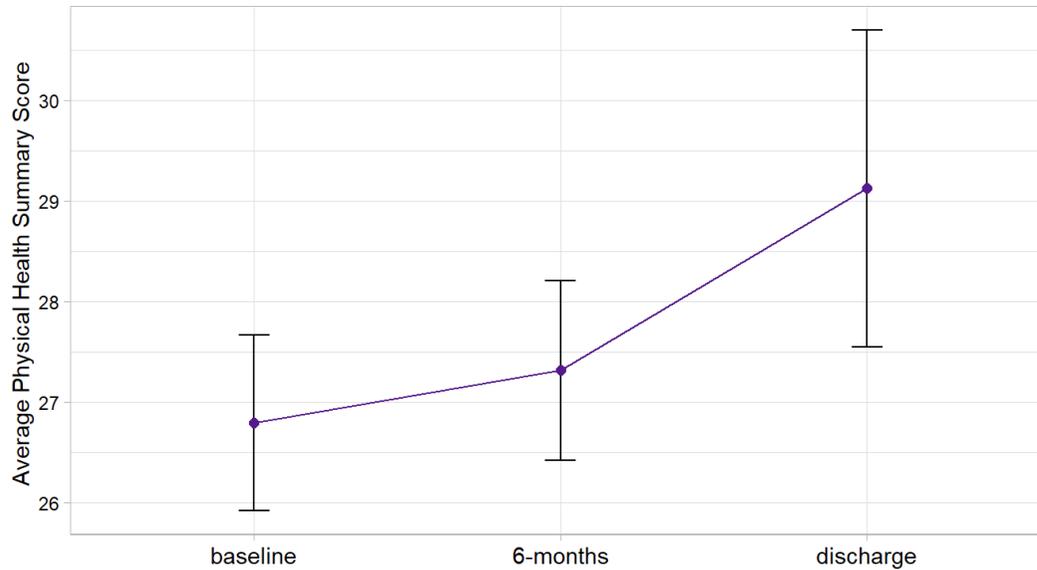
Energy/Fatigue from SF-36 (p=0.04)



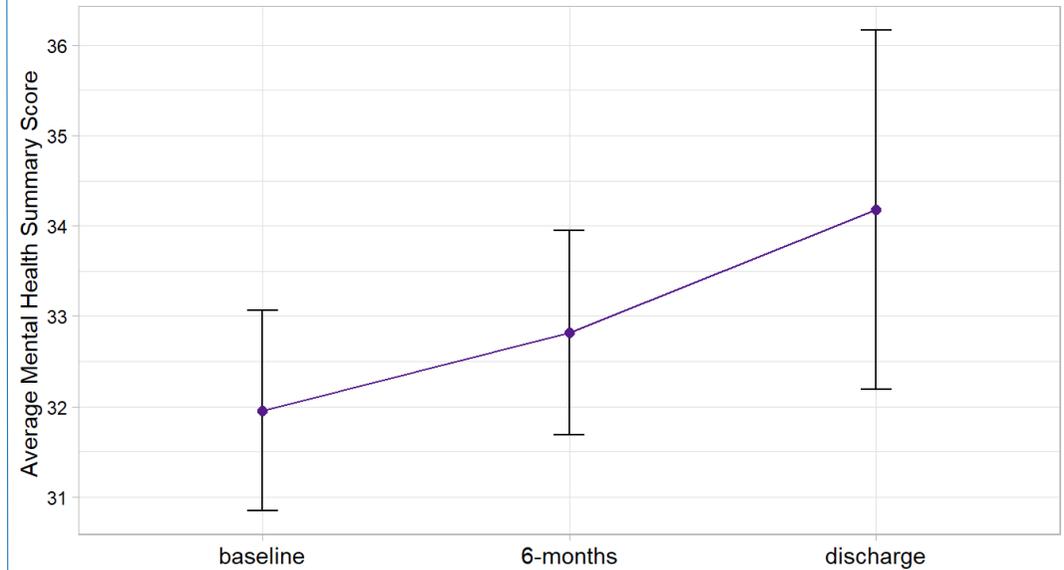
* controlling for age, sex and diagnosis

CCDP Data Registry selected outcomes

SF-36 Physical Health Summary Score (p=0.01)



SF-36 Mental Health Summary Score (p=0.01)



Can we make it work for patients?

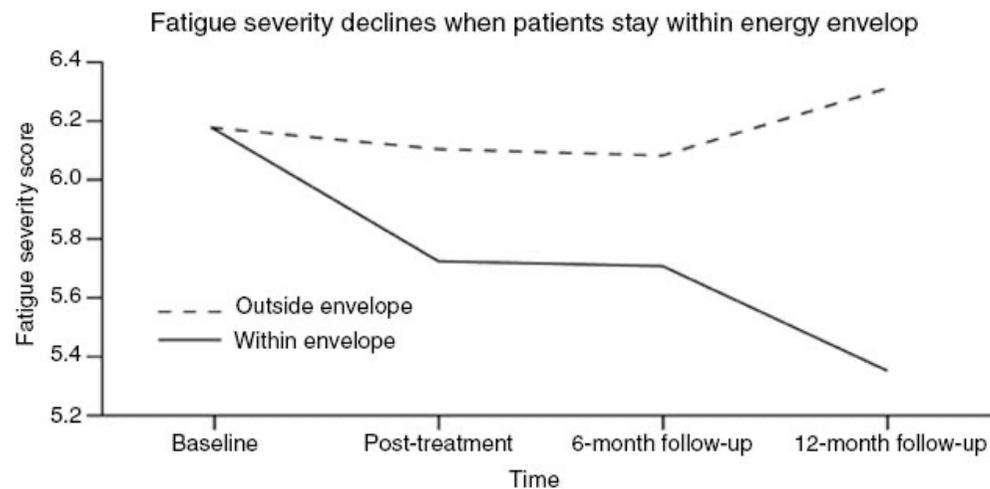
Evidence and patient- based care, with shared decision making

Caution on off-label medication use: needs patient-doctor agreement, balance of benefits and risks, and careful follow-up

Give personalised advice about illness management

There is no 'one size fits all' approach to managing symptoms

Plan activity to stay within their energy envelope and not push through activity
(NICE, 2021)



Jason, Benton, 2009



Start treatment early

Timing	No disease	Onset	0–4 months [†]	4–24 months*	2 years + [†]
Stage	Predisposition	Trigger and pre-illness	Prodromal period	Early disease	Established disease
Clinical phenotype	No symptoms	Non-specific or related to triggering “insult”	Fatigue-complex symptoms [‡]	Fatigue-complex symptoms [‡] variable severity and progress	Mild, moderate, severe and complicated disease
Prevention level [¶]	Primary prevention	Treatment of “insult” and primary prevention	Secondary prevention	Treatment and secondary prevention	Treatment and tertiary prevention
Recovery Potential [§]			Likely	Possible	Less likely
Pathophysiology	Predisposing factors	Non-specific host response and related to specific trigger factor	Neuro-immune response to insult and fight for homeostasis	Neuro-inflammation and systemic consequences; aberrant homeostasis	Systemic disease, aberrant or failed homeostasis

*3–6 months is commonly proposed as the minimum period of symptoms before diagnosis is made in children and adults, respectively (32).

[†] 2 years has been used as a cut off to distinguish between short and long term duration of disease (94, 95), but its use as defining established disease is variable and depends on a range of factors, including individual response to early disease.

[‡] Fatigue-complex symptoms: initially predominantly neuro-immune (prior to early disease), and variable systemic symptoms in established disease.

[§] Tentative proportions for recovery are: likely (>75%); possible (<20%); less likely (<5%). “Likely” and “possible” are based on recovery from arboviruses and EBV [(96); 100]; “less likely” is based on reviews on prognosis (97).

[¶] The Prevention level will be considered further in a subsequent publication which is being prepared by the authors.

Work in a System prepared to serve patients and responsive to their needs

EUROMENE RECOMMENDATIONS

- For fully functioning services, we recommend 2–4 ME/CFS specialist doctors/1 million population, with a supporting multi-disciplinary team, to include professionals such as nurses, nurse practitioners, occupational therapists, psychologists, dieticians, social workers, etc.
- The minimum desirable is one ME/CFS center providing specialist services for a 10 million population. These services should also consider the characteristics of the population, including ethnic and cultural diversity.
- Work with primary care and other professionals and with multi-sectors in society

Be a great health professional

REVIEW

THE AMERICAN
JOURNAL *of*
MEDICINE®

Ten Traits of Great Physicians

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ABSTRACT

There are certain traits that differentiate great doctors from good doctors. This article will discuss some of these traits along with tips you can incorporate to go from good to great. By applying these tips, I hope you will enhance your ability to practice medicine and improve your patients' experience.

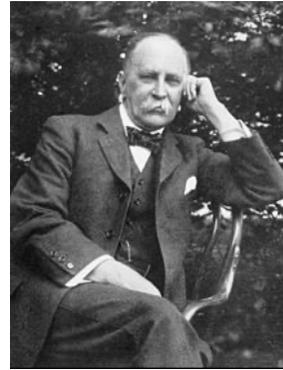
Published by Elsevier Inc. • The American Journal of Medicine (2023) 136:355–359

KEYWORDS: Communication; Doctor; Empathy; Qualities; Detective; Listener; Passion; Holistic medicine; Resilience; Detail; Relax; Physician; Traits; Tips

Be a great health ME/CFS professional

- Establish a partnership with the patient (and their supporters)
- Work as part of a multi-professional team (and with a network of external collaborators)
- Assess, diagnose, legitimize, address needs, support, treat
- Address pathophysiological abnormalities
- Educate and learn from patients and other professionals

Thank you!



“Listen to your patient; he is telling you the diagnosis.”

“A good physician treats the disease. The great physician treats the patient who has the disease.”

Sir William Osler

“People will forget what you said, people will forget what you did, but they will never forget how you made them feel.”

Maya Angelou

“It's attention to detail that makes the difference between average and stunning.”

Francis Atterbury.



Source: Alias Trate, 2020