Hope 4 ME & Fibro Northern Ireland

WHAT IS MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME (ME/CFS) ?

Building Bridges to a Better Future...

Our Story

Hope 4 ME & Fibromyalgia NI was founded by Joan McParland MBE in 2011 and officially established as a charity in 2014.

We are an all-volunteer led charity run by patients, family members, supported by medical and scientific experts: for people with Myalgic Encephalomyelitis (M.E.), Fibromyalgia, and Covid-induced M.E.. We are reliant solely on donations and small grants when available.

We provide vital support and advocacy for people with ME, Fibromyalgia and Long Covid across Northern Ireland, Ireland, and the UK.

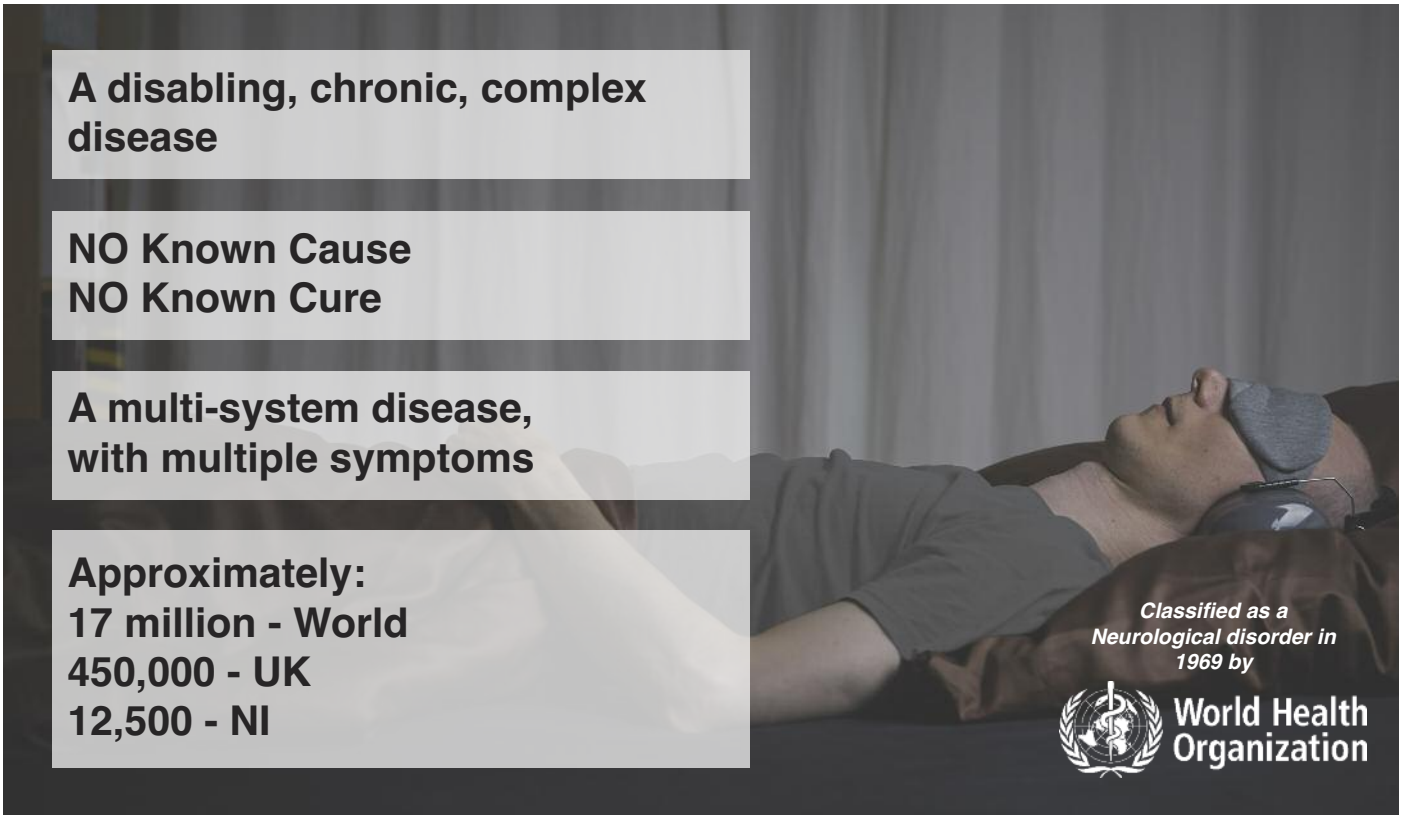
Our monthly Zoom support meetings, alongside annual conferences featuring leading experts, offer crucial lifelines to our community.

OUR IMPACT

From humble beginnings, Joan's vision has blossomed into a vibrant online community of 1000s of members and a team of dedicated volunteers. Supported by local councils and politicians, our charity spearheads efforts for specialist biomedical care in NI.

With prestigious awards and global recognition for our awareness initiatives, we're committed to empowering patients, driving research, and advocating for the best possible care.

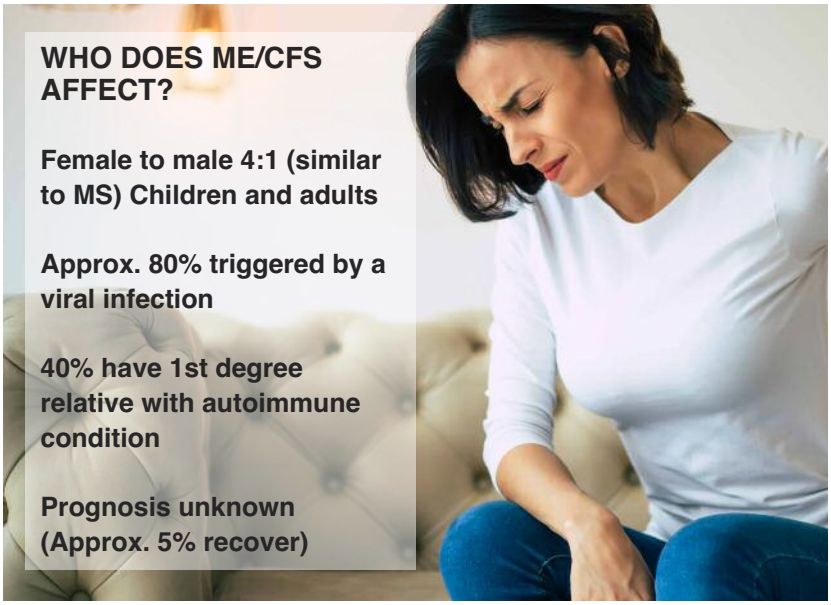
What is Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)?



WHAT CAUSES ME/CFS?

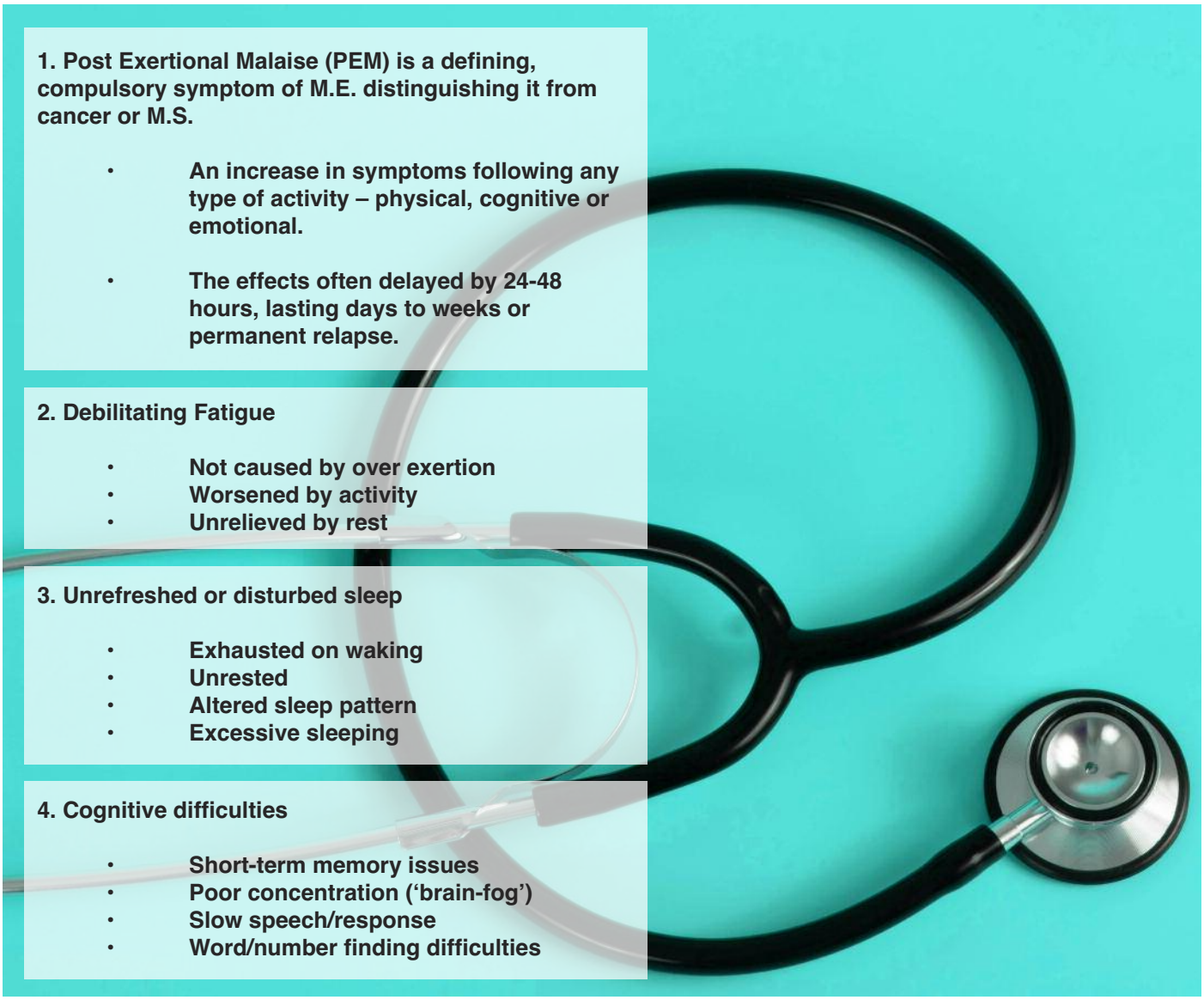
The cause is unknown, evidence indicates that there are likely to be a number of factors involved, and the illness may be prompted by an infection, virus, or some other triggering event.

ME/CFS can severely impact upon the person's ability to have a normal life. Many struggle with symptoms for years before receiving a diagnosis.



How is ME/CFS Diagnosed?

There is no specific laboratory test, a diagnosis is based on a person's medical history and symptoms, and by ruling out other diseases with similar symptoms. A diagnosis of ME/CFS is made by a doctor such as a GP or hospital consultant, ideally using the NICE Guideline (NG206) 2021 https://www.nice.org.uk/guidance/ng206 that requires the presence of 4 core symptoms:



1. Post Exertional Malaise (PEM) is a defining, compulsory symptom of M.E. distinguishing it from cancer or M.S.

- **An increase in symptoms following any type of activity – physical, cognitive or emotional.**
- **The effects often delayed by 24-48 hours, lasting days to weeks or permanent relapse.**

2. Debilitating Fatigue

- **Not caused by over exertion**
- **Worsened by activity**
- **Unrelieved by rest**

3. Unrefreshed or disturbed sleep

- **Exhausted on waking**
- **Unrested**
- **Altered sleep pattern**
- **Excessive sleeping**

4. Cognitive difficulties

- **Short-term memory issues**
- **Poor concentration ('brain-fog')**
- **Slow speech/response**
- **Word/number finding difficulties**

SUSPECT ME/CFS IN A PERSON IF THE FOLLOWING CAN BE APPLIED

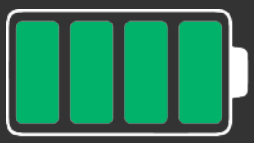
ALL 4 core symptoms have been present for a minimum of 6 weeks in adults, or 4 weeks in children and young people.

Significant reduction from pre-illness abilities to work, study, socialise, do other personal activities.

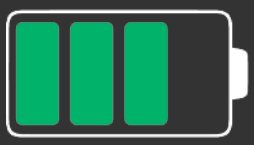
No other condition can explain symptoms.

Explaining Post Exertional Malaise (PEM) Or Post External Symptom Exacerbation (PESE) Using the Battery Analogy

Healthy



In the morning your battery is full.



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

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

Fully recharged again.

M.E.

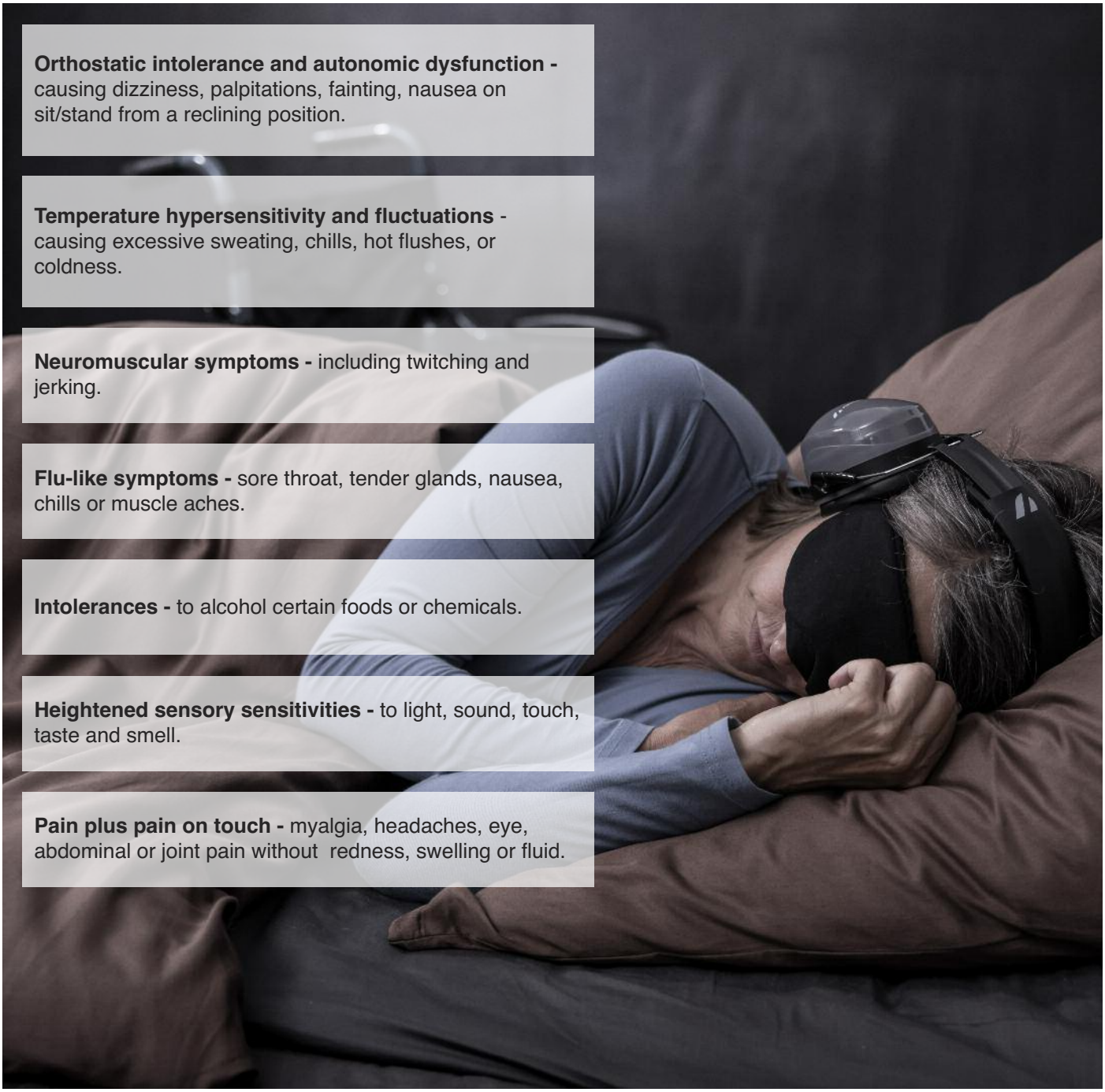
In the morning your battery is partly filled. This is your maximum attainable level.

Or in the afternoon after minimal, physical or mental activities, depending on your level of severity, your battery is draining fast.

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.

Other common symptoms of ME/CFS



Orthostatic intolerance and autonomic dysfunction - causing dizziness, palpitations, fainting, nausea on sit/stand from a reclining position.

Temperature hypersensitivity and fluctuations - causing excessive sweating, chills, hot flushes, or coldness.

Neuromuscular symptoms - including twitching and jerking.

Flu-like symptoms - sore throat, tender glands, nausea, chills or muscle aches.

Intolerances - to alcohol certain foods or chemicals.

Heightened sensory sensitivities - to light, sound, touch, taste and smell.

Pain plus pain on touch - myalgia, headaches, eye, abdominal or joint pain without redness, swelling or fluid.

Individuals experience different combinations and severity of these symptoms, which ultimately affects their ability to carry out every day personal, social, occupational, educational, physical, mental and emotional tasks and activities.

Severity Of ME/CFS

MILD, MODERATE, SEVERE, 25% SEVERE / VERY SEVERE

Individuals experience different combinations and severity of these symptoms, which ultimately affects their ability to carry out every day personal, social, occupational, educational, physical, mental and emotional tasks and activities.

People with M.E., have a lower quality of life compared to people with: M.S., lung & colon cancer, depression, heart & chronic kidney disease, and advanced HIV.

Treatment for ME/CFS

Currently, there is no effective drug treatment for ME/CFS, and rarely is a full recovery achieved.

However, through specialist support and the careful management of symptoms, these can be stabilised and improve with time.

In addition, achieving effective energy and activity management, to prevent flare-ups and relapses as a result of Post-exertional Malaise (PEM), is vital to achieve and maintain, some quality of life.

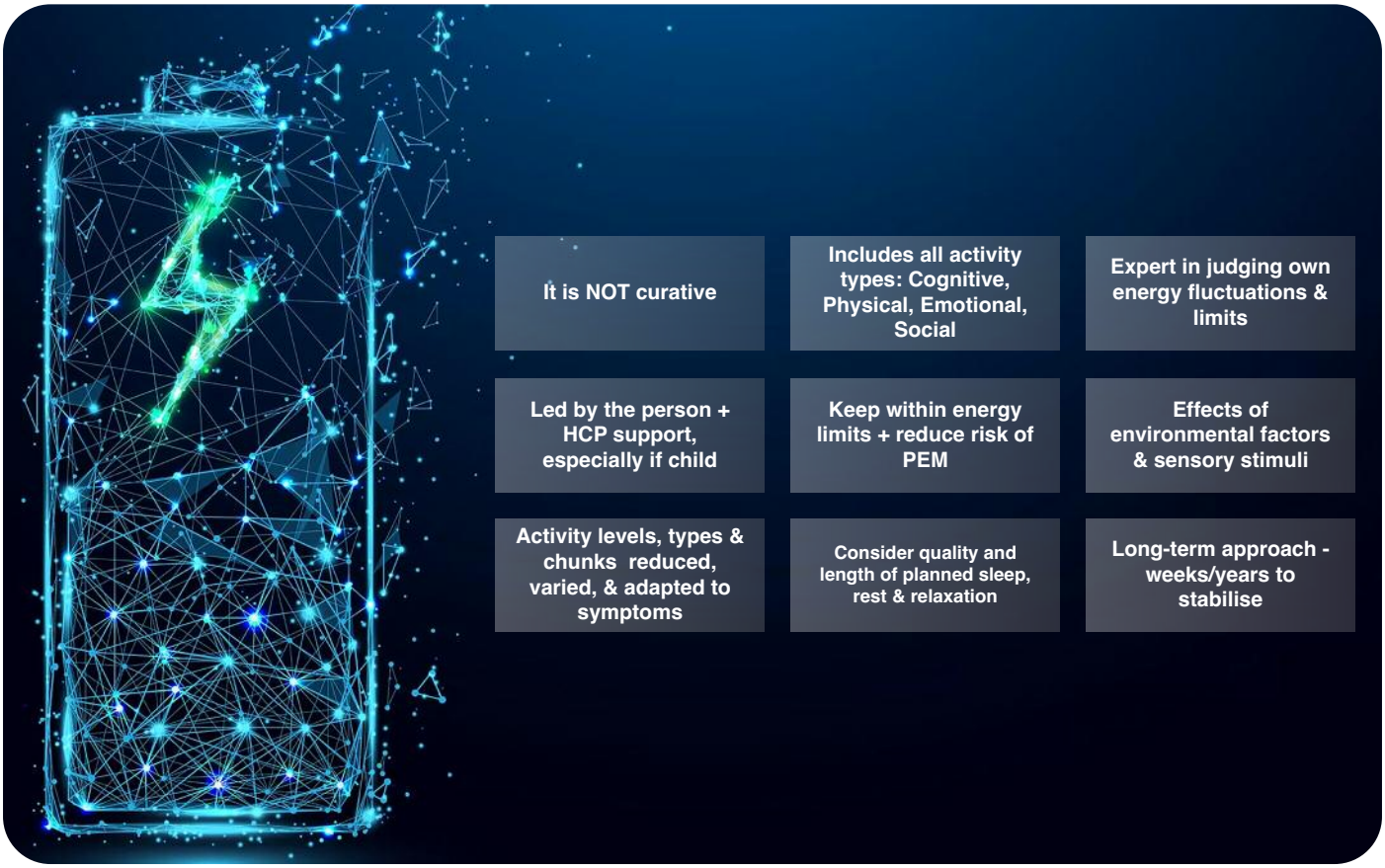
Globally ME/CFS research is ongoing; it is hoped that this will lead to a better understanding, and the development of preventative measures and treatments.

ENERGY MANAGEMENT

It is vitally important for anyone who has ME/CFS, to understand the benefits and risks of managing their energy and activities, and planning how to do it.

By setting an individual activity pattern within the persons current energy limits, symptoms can be minimised. Ideally, this should be done with the support of others – family, carers, friends and healthcare professionals (HCP), who can help the person to establish realistic expectations and meaningful personal goals.

Energy Management Planning in ME/CFS



ADDITIONAL IMPORTANT CONSIDERATIONS

Periodically review and agree the energy management plan (with support).

Be aware of how to manage flare-ups and relapses – as both can occur even when symptoms are well managed.

Tools can be used to aid the self-monitoring of activities such as: activity trackers and apps, phone (or other) heart-rate monitors, or diaries.

WHAT DO PEOPLE WITH ME/CFS NEED?

Compassionate care and support to manage energy

Mobility aids

Regular medical review with a doctor

Some will need full-time care

Very severe ME/CFS:

- Need help with personal hygiene and eating.
- Awareness of extreme sensory stimuli sensitivity.
- Those unable to swallow, may need tube fed.

Other Forms of Support for People with ME/CFS

Points of contact – when support needed E.g. social care, financial, benefits

Support to manage daily activities – family, caring roles, education, interests & employment

Sources of advice & support –support groups, online forums, disability sites, apps.

Support to manage symptoms – medication, energy management, rest, priorities & meaningful activity

Multi-disciplinary rehabilitation –appropriate, safe & monitored

Additional Support for Vulnerable Groups, Children, Young People and those with Severe/Very Severe ME/CFS

Additional support from social services may be required for 'vulnerable groups' such as – the elderly, or those with complex physical or mental health needs.

Referral to a specialist Paediatrician should be made for children and young people (under 18), when ME/CFS is suspected as per 'NICE ME/CFS Guideline 2021'.

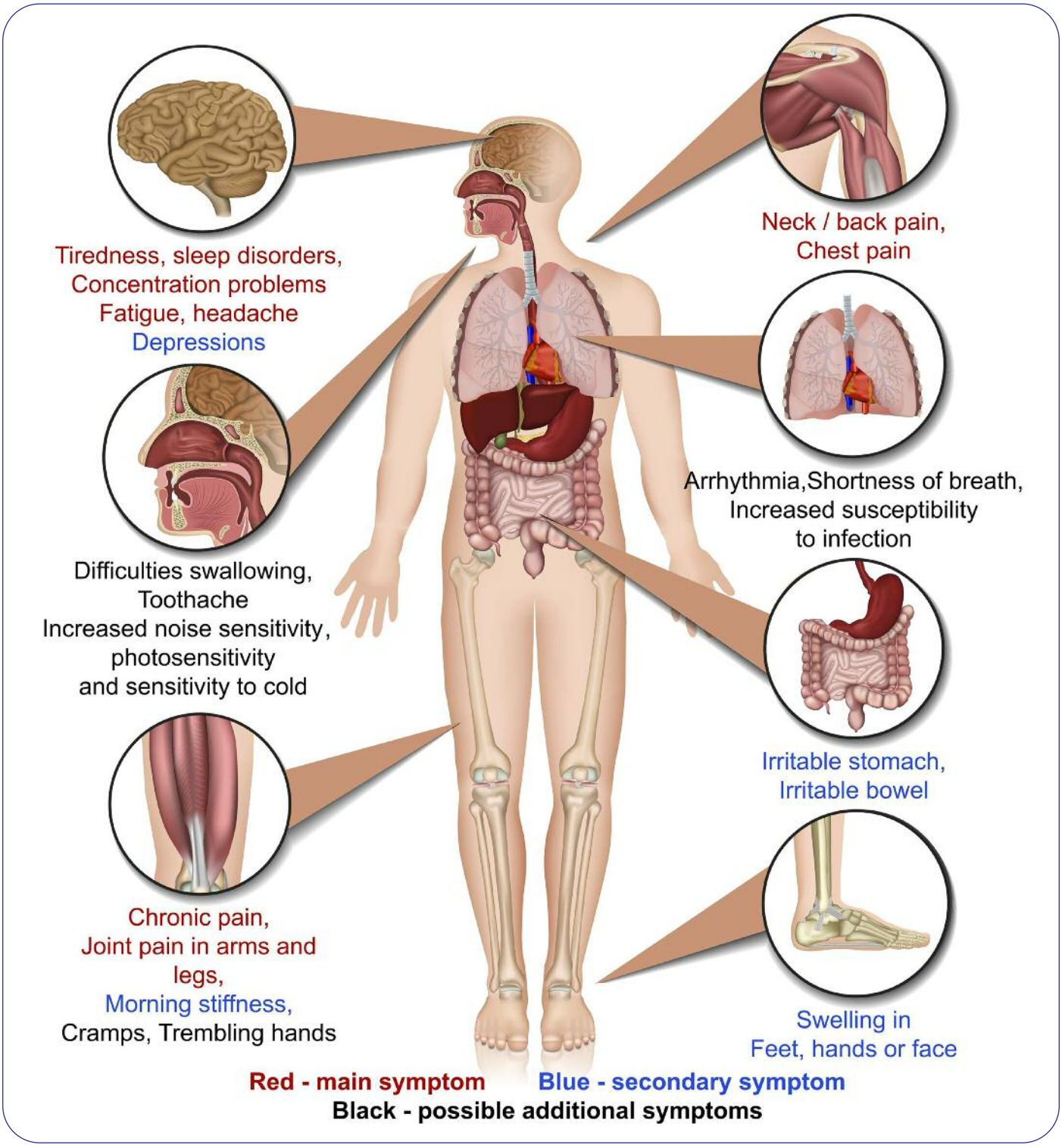
Children and young people with ME/CFS, should have their care and support reviewed at least every 6 months, or more frequently as necessary, and depending on how severe and complex their symptoms are.

Those with Severe ME/CFS, often experience difficulty in accessing health services and in voicing their needs, both in the community and hospital settings.

Engaging the support of a sympathetic GP from the beginning, can go a long way to alleviating many of these issues, however this is not as easy as it should be.

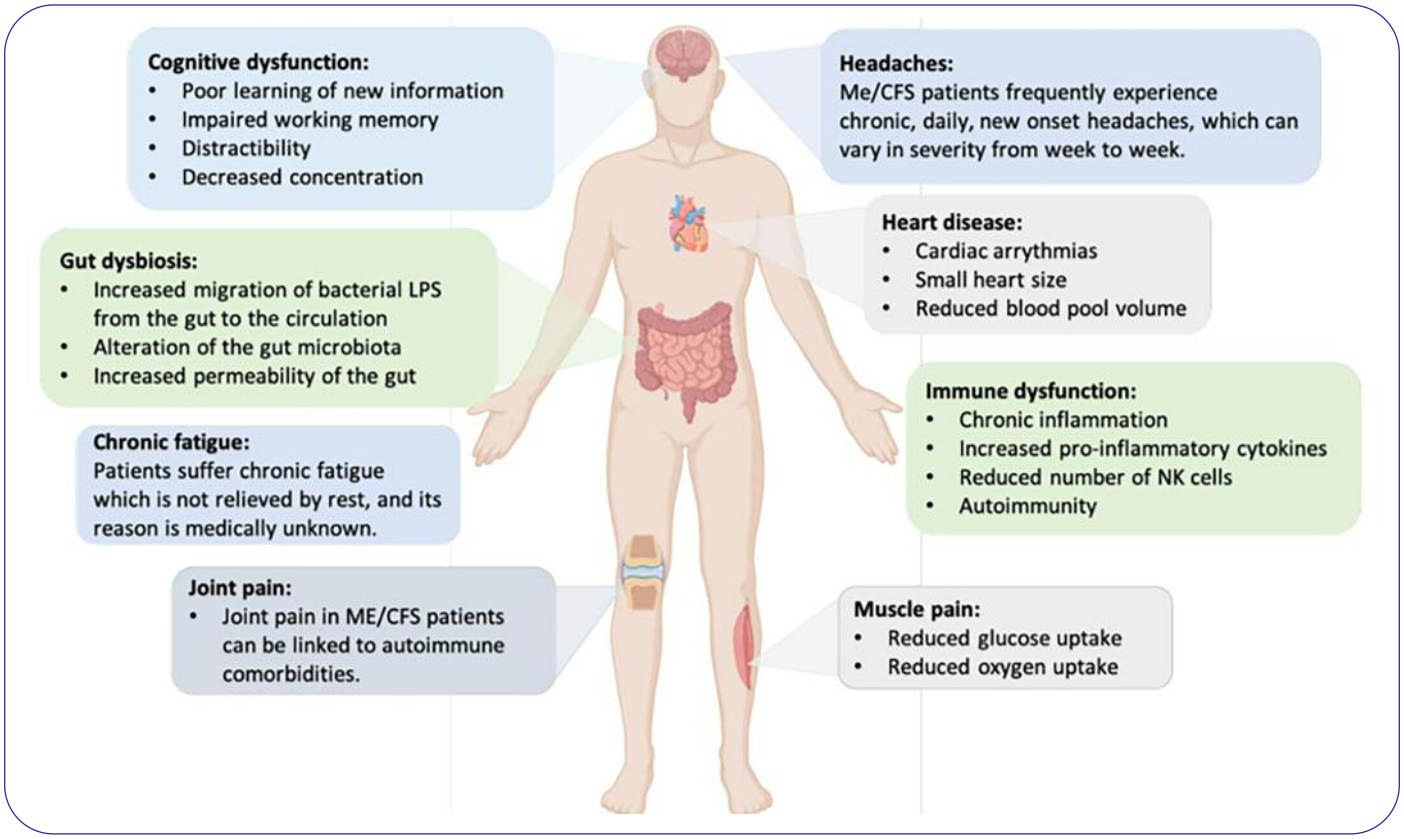
The Overlap In Symptoms Of M.E. And Fibromyalgia

Fibromyalgia Symptoms



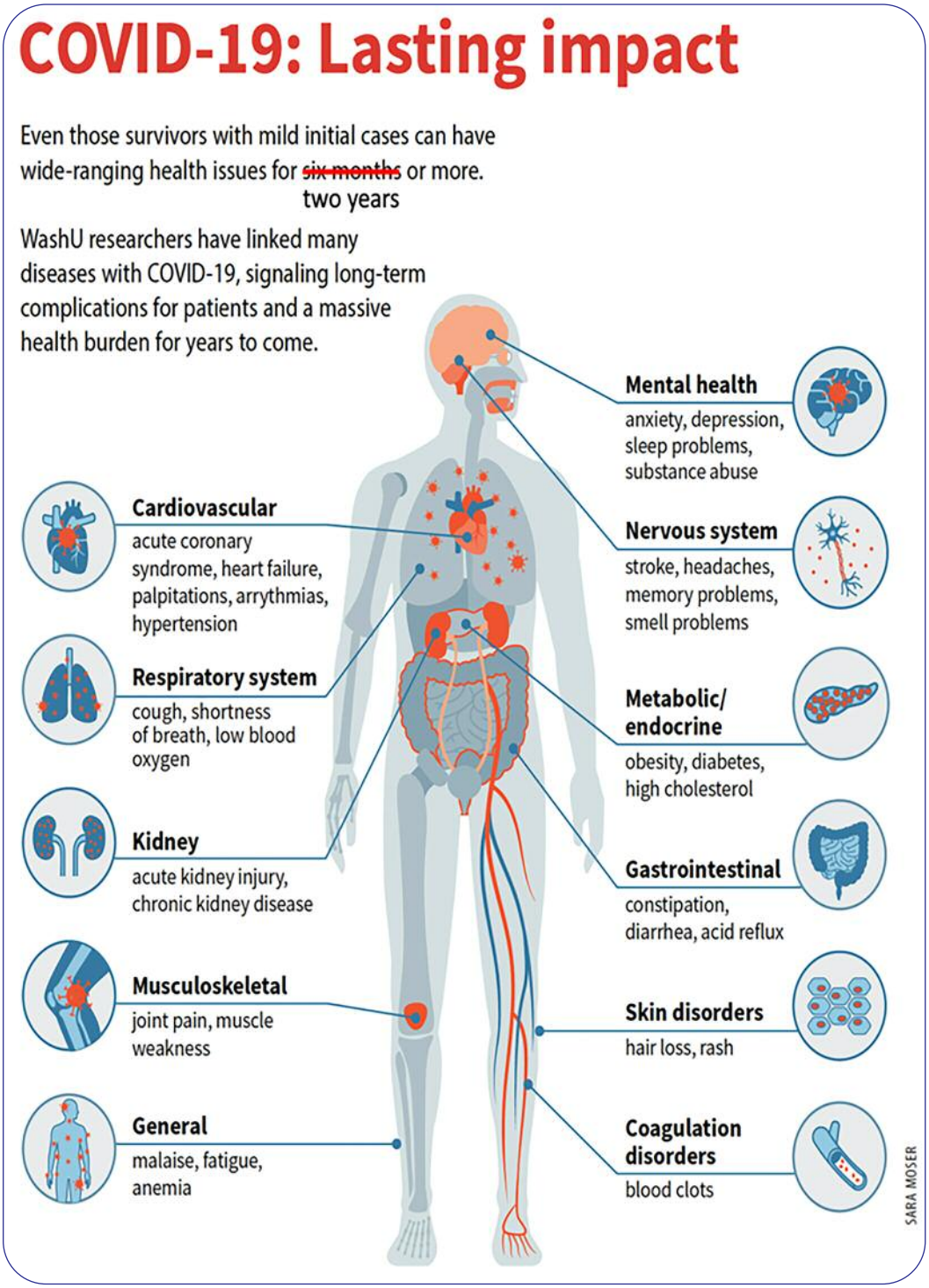
The Overlap In Symptoms Of M.E. And Fibromyalgia

ME/CFS Symptoms



You can scan (printed version) the QR Codes throughout this document OR you can TAP the QR Codes if viewing on any screen

M.E. And Long Covid Overlap



DID YOU KNOW

Globally -
65 million people are estimated to have Long Covid

50% approx. of those with Long Covid have M.E.-like symptoms

England & Scotland – approx. 2million
(ONS March'24)

USA –
approx. 17.6 million adults
(CDC March'24)

CASE STUDY: David Campbell

Lisburn Man David Campbell's Fifteen-Year Struggle Highlights M.E. Challenges in Northern Ireland

Lisburn man calls for urgent action on M.E. services

For David Campbell, 35, thousands of people in Northern Ireland with Myalgic Encephalomyelitis (M.E.), also known as Chronic Fatigue Syndrome, are being failed by politicians and the Department of Health.

David has lived with M.E. for 15 years and says there are no specialist services in NI, little research, and widespread misconceptions about the condition. “Either attitudes need to change, or the people in those positions need to,” he says.

Speaking as part of the Discover ME campaign by Hope 4 ME & Fibro NI, David supports efforts to raise awareness of M.E., Fibromyalgia, Long Covid and other post-viral syndromes.

The campaign includes VR film screenings across 13 libraries and landmark buildings lit in blue on World ME Day. Around 7,500 people in NI are thought to have M.E., with 30,000 showing similar symptoms due to Long Covid.

David’s symptoms began in his second year at university after a trip to Israel and Palestine. Once active and social, he became exhausted, developed insomnia, memory and concentration problems, and had to leave his studies.

His GP was supportive but admitted little knowledge of M.E., while some specialists dismissed the condition entirely.

M.E. is far more than “being tired.” It causes post-exertional malaise, where even small physical or mental effort can trigger days of worsened symptoms. On good days, David might manage a short walk or coffee; on bad days, he is bedbound in a dark room. Severe cases can leave people unable to walk, tolerate light or sound, or even feed themselves.

CASE STUDY: David Campbell

David relies on careful planning and the support of family and friends. Still, M.E. has cost him his education, much of his social life, and many relationships. “It’s robbed me of my 20s and is taking my 30s,” he says.

He is calling for long-term specialist services, biomedical research, and greater understanding of how debilitating M.E. can be.

“Even basic tasks like reading, cooking, or taking notes on a phone call can be impossible. The reality of M.E. needs to be recognised.”

You can read the full case study on our website

Links to Additional Resources and Support on ME/CFS

NI Direct Health Conditions A-Z
https://www.nidirect.gov.uk/conditions/myalgic-encephalomyelitis-chronic-fatigue-syndrome-me-cfs

M.E Association
https://meassociation.org.uk

Action for M.E
https://www.actionforme.org.uk

Invest in M.E
https://www.investinme.org/index.shtml

World M.E Alliance
https://worldmealliance.org

Bateman Horne Center
https://batemanhornecenter.org/education/me-cfs/

Tymes Trust
https://www.tymestrust.org

25%M.E Group
https://25megroup.org

There For ME
https://linktr.ee/ThereForME

Like

Please donate

Change starts here.

PayPal Donate

Give as you Live Donate

Join our Discussion Forum

Building Bridges to a Better Future

Hope 4 M.E and Fibro N.I
25 Mc Shane's Road I Bessbrook I Newry
Co. Down I Northern Ireland I BT35 7LZ

T: +44 (0) 77 1289 2834
E: hope4mefibro@outlook.com
W: www.hope4mefibro.org

The Queen's Award for Voluntary Service
The MBE for volunteer groups

Registered with the Charity Commission for Northern Ireland. Charity No. NIC100184