

# MEE Medical

The magazine for Healthcare Professionals



4  
The new NICE  
Guideline on  
ME/CFS

6  
The IACFS/ME  
Conference

8  
Anxiety and  
Panic Attacks

11  
Dr Charles  
Shepherd's  
Medical Q&A

14  
The Pathology of  
Central Fatigue  
Disorders

16  
Surviving M.E.





This ME Association magazine has been designed solely for doctors and healthcare professionals. It has been estimated that ME/CFS affects around 265,000 adults and children in the UK, so the chances are you will come into contact with someone who has this medical condition.

We hope this quarterly magazine will help to keep you informed of recent developments and contribute to your own understanding. We would like to thank you and your colleagues for the support and help you provide to people with ME/CFS.

If you have any questions then please get in touch: [contact@meassociation.org.uk](mailto:contact@meassociation.org.uk).

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## About The ME Association

### Biomedical Research

We invest in essential research to discover what causes ME/CFS so that effective treatments can be developed. We are the only charity that funds the vital UK M.E. Biobank in central London.

### Information & Support

We are here to support people with ME/CFS so that everyone gets the help they need. We provide timely and accurate information via an extensive library of leaflets and the telephone helpline. MEA literature can be found online here: <https://meassociation.org.uk/me-association-shop/>

### Trustees & Staff

Everyone who works for the charity has experience of ME/CFS, is currently living with the condition, or has a loved one or close friend that has been affected.

### ME Connect

The telephone helpline is available 365 days a year to offer support, advice and a listening ear.

The number for ME Connect is **0344 576 5326**. We have a wonderful team of volunteers who are available 10am-12noon; 2pm-4pm; and 7pm-9pm. More information about ME Connect can be found here: <https://meassociation.org.uk/about-the-mea/telephone/>

### Membership

We have kept membership subscriptions affordable from just £18 a year, because we know how much of a lifeline ME Essential magazine can be. We put our members' interest at the forefront of all that we do.

Full Membership is available to all adults with ME/CFS, carers and anyone with an interest in the disease. Annual membership costs: £18.00 (UK residents and BFPO); £24.00 (Mainland Europe including Republic of Ireland); £30.00 (Rest of the World)

Join the MEA here: <https://meassociation.org.uk/product-category/mea-membership/>

### Collaborations

We collaborate with other charities and belong to Forward-ME and the CFS/ME Research Collaborative (CMRC) because there are times when we need to speak with a single voice and share investment in research.

### Fundraising

We are so grateful to every fundraiser – not just for the valuable funds that they raise, but also for the awareness that comes with every single event. ME/CFS still has a long way to go to achieve the kind of medical recognition and social acceptance that other diseases like M.S. have obtained, and any effort on your part can help spread the word and bring us closer to these objectives.

<https://meassociation.org.uk/donate/>

## Welcome to MEE Medical

Introduction by  
Dr Charles Shepherd,  
Hon. Medical  
Adviser to the  
ME Association



### WHY YOU HAVE RECEIVED THIS PUBLICATION

You have received MEE Medical, our new magazine for health professionals, because a patient has requested it be sent to you. If you would also like to receive the members magazine ME Essential, please join the ME Association as a member: <https://tinyurl.com/yu89nuzx>

ME Essential features exclusive articles, medical and scientific developments, Ask the Doctor, stories and opinions from people living with ME/CFS, and keeps members apprised of recent news. Quite simply, it is the best magazine available and the feedback we receive proves it!

### Dear Healthcare Professionals

Welcome to your free magazine from the ME Association. It contains news, medical and research information about Myalgic Encephalomyelitis/Chronic fatigue syndrome (ME/CFS) that we hope you will find helpful and enjoy reading.

#### Winter vaccinations

We are now focused on the Winter vaccine season and helping people with ME/CFS obtain the Flu, Pneumococcal, and/or Covid booster vaccinations if they decide to have them.

New infections pose a significant risk to people with ME/CFS because they are likely to lead to an exacerbation of symptoms and possibly a relapse.

We therefore feel that people with ME/CFS are entitled to these vaccines on the NHS if they choose to do so and to be treated as clinically vulnerable. Many were able to obtain priority treatment for the earlier Covid vaccinations under JCVI group 6 criteria, so we hope obtaining vaccinations will be less onerous for patients this time round.

Some people have reported short- to medium-term reactions to previous Flu and Covid vaccines in particular, which can exacerbate their primary symptoms and cause relapse. It's not clear if these are reactions to the vaccines themselves – although there is research evidence suggesting this might be the case – or because of post-exertional malaise (PEM).

PEM is a characteristic symptom of ME/CFS and can be triggered when a person who is normally restricted to home or bed because of poor health is suddenly faced with having to do an activity – like attend a surgery or vaccine centre – that requires more energy than they might have. Even if they carefully plan and have support during the activity, it can leave them in worse health for a long time afterwards.

In such situations it would be very helpful if people with ME/CFS – especially those who are so severely ill they are bedbound for all or most of the time – could be offered a vaccine at home.

For the majority with ME/CFS, it would be really helpful if doctors can record their patient's clinically vulnerable status, make them a priority for vaccination, and offer them a Flu vaccine.

#### NICE Guideline ME/CFS

The new NICE guideline has now been published and the news relating to this is featured in this magazine. You can read the full NICE Guideline here: <https://www.nice.org.uk/guidance/ng206>

#### Research

The charity's research correspondent, Katrina Pears, has been covering the IACFS/ME conference in Florida and we have included a selection of the presentations that took place.

Dr Abhijit Chaudhuri talks about ME/CFS, the NICE guideline, the unique energy problems in ME/CFS, graded exercise, and the causes and potential treatments for neurologically-induced fatigue.

Physios 4 ME have launched a public survey asking people with ME/CFS about their experience of using a heart-rate monitor to help pace activities. Current research indicates that people with this condition often have dysautonomia and that, when they push themselves too hard, this results in an abnormal increase in heart rate. This can be monitored to help them slow down, plan, and then attempt an activity in such a way that doesn't trigger the increase. Some people find the method helpful, while others find it a distraction and too much effort.

I really hope you enjoy this Winter issue of the magazine. If you have any comments about the content, or have any questions about ME/CFS, please let me know by emailing [contact@meassociation.org.uk](mailto:contact@meassociation.org.uk)

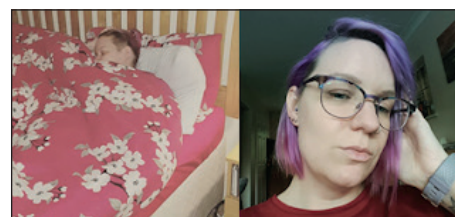
Kind regards,

**Dr Charles Shepherd, Hon Medical Adviser, MEA**



## The new NICE Guideline on ME/CFS

*Dr Charles Shepherd, who was a member of the committee that prepared the new guideline, comments:*



### NICE have now published the final version of the new guideline:

<https://tinyurl.com/4kbs87cm>

People with ME have had to live with a NICE guideline for almost 15 years that was unfit for purpose - because it recommended treatments that were either ineffective or harmful.

After a very thorough review of all the evidence - from clinical trials, experts and patients - we now have a new guideline that has reversed these recommendations and should be widely welcomed by people with ME.

### In particular the new guideline...

1: Recognises that ME is serious and complex medical disease.

2: Emphasises the need for early and accurate diagnosis - preferably within 3 months of the onset of symptoms, which normally follow an acute viral infection, and where there are important overlaps with Long Covid.

3: Provides sensible guidance on activity and energy management in order to avoid symptom exacerbation and no longer recommends GET.

4: Recognises the special problems faced by children and those with severe ME.

The next challenge involves educating and training all

health professionals on how to diagnose and manage ME and setting up a full network of hospital-based referral services where GPs can refer for further help.

### Coverage from Pulse:

<https://tinyurl.com/3rmxesd5>

by Emma Wilkinson

NICE's final guideline on the diagnosis and management of myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS) has recommended that patients receive a 'personalised care and support plan'.

Today's publication of the final guideline comes as NICE halted the publication of the long-anticipated update in August because of 'strong views' around management of the condition.

Much of the debate appeared to be around recommendations to not use graded exercise therapy (GET) and CBT as treatments for the condition.

It was reported that several members of the guideline committee had walked out over the fallout and the delay prompted heavy criticism from patient groups and charities.

After a 'successful' roundtable discussion to address concerns that had been raised by some professional bodies, NICE said it was now confident that the guidelines, which cover children,

young people and adults could be effectively implemented across the system.

ME/CFS is a complex, multi-system, chronic medical condition where there is no 'one size fits all' approach to managing symptoms, the NICE guidelines stress.

It outlines the condition as debilitating fatigue that is worsened by activity, post-exertional malaise, unrefreshing sleep or sleep disturbance, and cognitive difficulties described as 'brain fog'.

People with all four symptoms that have lasted three months or more should be referred to a specialist team and a range of management approaches should be offered depending on an individuals' preferences and priorities, the guidelines state.

But any programme based on fixed incremental increases in physical activity or exercise such as GET, should not be used, NICE said. No therapy based on exercise or physical activity should be given as a 'cure'.

Personalised exercise programmes can be offered in people with ME/CFS who want the option but it should be overseen by a specialist physiotherapist and reviewed regularly.

NICE said discussions during the guideline pause highlighted that the term 'GET' is understood in

different ways and they have set out clear definitions.

The committee recommend that person-centred energy management can be offered as a key component of a personalised management plan. Reviewed regularly, it can help people understand their energy limits so they can reduce the risk of overexertion worsening their symptoms.

NICE also said that although CBT has sometimes been assumed to be a cure for ME/CFS, it should only be offered to support people who live with ME/CFS to manage their symptoms, improve their functioning and reduce the distress associated with having a chronic illness.

Paul Chrisp, director of the Centre for Guidelines at NICE, said: 'As well as bringing together the best available scientific evidence, we've also listened to the real, lived experience and testimony of people with ME/CFS to produce a balanced guideline which has their wellbeing at its heart.'

Peter Barry, consultant clinical advisor for NICE and chair of the guideline committee, said the guideline would provide clear support for people living with ME/CFS, their families and carers, and clinicians.

'We know that people with ME/CFS have had difficulty in getting their illness acknowledged, and the guideline provides guidance

for suspecting and diagnosing the condition, recognising that there is no specific test for it.

'The guideline emphasises the importance of a personalised management plan for areas such as energy management – including the importance of rest and staying within the individual's energy limits – the treatment of specific symptoms, and guidance on managing flares and exacerbations.'

Dr Charles Shepherd, medical advisor to the ME Association and one of the committee members from 2019 until he stood down this year, said: 'This is a very special day for people with ME – publication of a new evidence-based NICE guideline which confirms that this is a serious and very debilitating medical disease.

"I particularly welcome the emphasis on early and accurate diagnosis and the need to provide early guidance on symptom management when people are not recovering from a viral infection and a diagnosis of ME is suspected.

"This new guideline will have a big impact on care for people with ME, and draws a line under the damaging therapies of the past." ■

#### **A few of the NICE Guideline highlights:**

##### **Be aware that ME/CFS:**

- is a complex, chronic medical condition affecting multiple body systems and its pathophysiology is still being investigated

- affects everyone differently and its impact varies widely

- is a fluctuating condition in which a person's symptoms can change unpredictably in nature and severity

##### **Healthcare professionals should recognise that people with ME/CFS need:**

- timely and accurate diagnosis so they get appropriate care for their symptoms

- regular monitoring and review, particularly when their symptoms are worsening, changing or are severe

##### **Suspect ME/CFS if:**

- the person has had all of the persistent symptoms in box 2 for a minimum of six weeks in adults and four weeks in children and young people and

- the person's ability to engage in occupational, educational, social or personal activities is significantly reduced

- symptoms are not explained by another condition

##### **Do not offer people with ME/CFS:**

- any therapy based on physical activity or exercise as a cure for ME/CFS

- generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses

- any programme that does not follow the approach in recommendation 1.11.13 or that uses fixed incremental increases in physical activity or exercise, for example, graded exercise therapy ■

Source: NICE: <https://www.nice.org.uk/guidance/ng206>



## Dialogues for a neglected illness

This short film explains Myalgic Encephalopathy/Encephalomyelitis (M.E) also known as Chronic Fatigue Syndrome (CFS) with quotes from knowledgeable healthcare professionals including our honorary medical adviser Dr Shepherd. It highlights post-exertional malaise (PEM), the risks of Graded Exercise Therapy (GET) and the importance of the new NICE guideline for ME/CFS.

There are many excellent videos available on the Dialogues of ME/CFS website: <https://www.dialogues-mecfs.co.uk>

Dialogues for a neglected illness (Dialogues for ME/CFS) is a project made possible by an award from the Wellcome Public Engagement Fund. (Sept 2018 - Sept 2021).

"What a lot of pain and heartache could be spared if all doctors were properly informed and able to guide their patients in those crucial early stages."

Kay Gilderdale

Kay's daughter Lynn died after sixteen years of very, very severe ME, precipitated by graded activity management. ■

## From the MEA website

### **Will there ever be a test for chronic fatigue syndrome?**

An article written by Chloe Kent appears in the Medical Device Journal asking whether there is likely to be a definitive test for ME/CFS and the dangers of a test that does not identify all people with the illness: <https://tinyurl.com/zj6csk7t>

### **A new treatment for Long Covid?**

A potential new treatment for Long Covid that is being assessed in Germany, where it has been used on just over 100 patients so far. The treatment (known as apheresis) is based on the fact that Covid can cause blood clots (micro-clots) and damage to the lining of small blood vessels and this may also be a causative factor in Long Covid: <https://tinyurl.com/6tzdrzt3>

### **Royal College of Nursing: From Chronic Fatigue Syndrome to Long Covid**

Senior nurse Michelle was already suffering from chronic fatigue when the COVID-19 pandemic struck. After she caught the virus, chronic fatigue services helped her manage some ongoing symptoms, but accessing specialist long COVID support hasn't been as easy. Michelle tells us her story: <https://tinyurl.com/4dseu3zf>

### **GP appointments**

The Government drive to get more face-to-face Doctor appointments after the increased use of online consultations during the pandemic lockdown periods: <https://tinyurl.com/7s3d888z>

**NICE** National Institute for Health and Care Excellence

## The IACFS/ME Conference

**The 2nd Virtual Scientific Conference for the International Association for Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis was held on the 19th – 21st August 2021 (streamed on zoom). The conference promoted unpublished data and included both clinicians and biomedical researchers.**

The talks were grouped into different sections, including the longer 45-minute talks in the Professional Workshops and shorter talks covering topics of infectious diseases, immunology and clinical cases.

We have chosen a selection of the talks which will hopefully be of interest to you. These are listed below. We begin with the presentation from Dr Alison Bested giving an overall background to ME/ CFS, titled “Clinical Pearls to Diagnose and Treat Myalgic Encephalomyelitis/Chronic Fatigue Syndrome”. The rest of the reviews will follow.

Due to the format of the conference and the focus on unpublished data, no direct recordings or pictures are freely available as this may jeopardise publication. The full conference programme can be found here and recordings may be purchased on the IACFS/ME website.

International Association for

**IACFS/ME**

Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis

### **Clinical Pearls to Diagnose and Treat Myalgic Encephalomyelitis/Chronic Fatigue Syndrome**

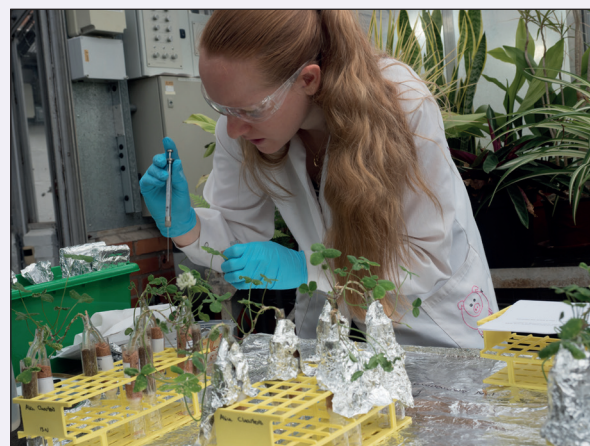
**Alison Bested, MD, FRCPC, ABOIM**

**Chair, Integrative Medicine, Associate Professor Nova Southeastern University; Weston, FL, USA**

Dr Bested is a specialist in haematology (specialist area in diagnosis and management of problems with blood cells) and her work is dedicated to helping people with chronic illnesses. At the start of the talk, she acknowledged her patients for teaching her so much. This presentation is primarily for practitioners to improve teaching and diagnosis of ME/CFS and gives a good background to the illness. The take-away message is to make an early and accurate diagnosis which will help the patient the most.

The talk began with the history behind ME/CFS. It is not a new illness and has been seen in history since around 1400 BC. ME/CFS is a multiple organ illness and involves immune and autonomic dysfunction.

Dr Bested went through how to make a diagnosis: take a family history, do a physical examination, and take laboratory tests to rule out other illnesses. Different diagnostic criteria were looked at: the IOM diagnostic criteria which covers five main symptoms and the ME/CFS Canadian Clinical working case



**Katrina Pears, Research Correspondent for the ME Association,** reports on the IACFS/ME Conference



criteria which covers a larger range of symptoms. A clinical criteria worksheet checklist can also be used to rule out other illnesses.

She then went through the pathophysiology of ME/CFS and the fact that all bodily systems are involved, including genetics and metabolism. Research studies showing differences compared to healthy controls were briefly covered. These included: genetics, cognitive dysfunction, autonomic and cardiac dysfunction, immune dysfunction, neuroinflammation, muscle metabolism, abnormal aerobic metabolism, stressors and microRNAs.

Dr Bested reviewed supportive symptomatic care which looks at managing symptoms and a whole-person holistic approach (including income, support systems, living situation).

The importance of making a diagnosis was stressed, as it helps to achieve better outcomes, and the person can begin to heal. Pacing was stressed as the single most important form of self-management; GET and pushing to do more were acknowledged as harmful. It was important to understand, she said, that every activity costs energy, and activities should be alternated with rest. Activity logs can be used to see patterns and help prevent crashes.

In her opinion, management approaches also need to cover:

■ **Diet and nutrition:** Food that is not as processed and contains fewer chemicals can mean less inflammation. Problems with food security which means no income for meals or no support to make meals. Gut imbalances and food sensitivities should also be considered,

■ **Sleep hygiene:** pace to avoid being “over-tired and wired”, and the role of meditation which is better than medication (i.e. non-drug approaches),

■ **Cognitive problems:** how to manage over-stimulation,

■ **Pain:** how to treat and self-manage.



Fundamentally, the approach to management needs to look at rebalancing the whole system, including support, exercise (even if just steps), sleep, environment and diet. Furthermore, it is critical to have regular follow-ups with a physician, investigate all new symptoms which develop and also any worsening of symptoms.

(N.B. there was change in the running order of the presentations. This talk is the third listed in the programme).

## PROGRAMME OF OTHER EVENTS

with links to our blog reviews

## PROFESSIONAL WORKSHOPS

**Dysautonomia: Blair Grubb, MD,** University of Toledo; Toledo, OH, USA

Dr Blair Grubb is a distinguished university professor of medicine and paediatrics. His talk focused on research into POTS (Postural Tachycardia Syndrome). Dr Grubb's talk started with an introduction to the autonomic system which regulates all systems in the body which keep you alive, for example blood pressure, heart rate, temperature and gut processes (our bodies have no control over these processes). Dr Grubb went on to explain the role of the autonomic system involving the brain and heart



upon standing, and the role of the skeletal-muscle pump.

Dr Grubb then gave a brief background to the five distinct ANS disorders (Autonomic Nervous System)- NCS, POTS, Dysautonomia, cerebral syncope and psychogenic syncope. Fatigue is a major component of all of these. Dr Grubb's talk then focused on POTS, definition and its history.

Dr Grubb's research is currently investigating if POTS is an autoimmune disorder, due to onset often following a viral infection (75% of cases); it frequently exists in people who already have autoimmune disorders or go on to develop other autoimmune conditions. Evidence for POTS as a autoimmune condition has previously been found, but it's not until the last 10-15 years that technological advances have allowed cost-effective research.

<https://tinyurl.com/45k5uvks>

## Emerging treatment options for autoimmune ME/CFS:

**Carmen Scheibenbogen, MD** Institute for Medical Immunology, Charité University Medicine (Germany): <https://tinyurl.com/yw9w3p3k>

## Mast Cell Activation Disease: Current Concepts: Larry Afrin, MD

AIM Center for Personalized Medicine; Purchase, NY, USA: <https://tinyurl.com/2y7w3e6z>

## KEYNOTE

**ME/CFS and Long-COVID: overlapping or distinct entities: Avindra Nath, MD** US National Institutes of Health, NINDS; Bethesda, MD, USA

## INFECTIOUS DISEASE

**COVID-19 Symptoms Over Time: Comparing Long-Haulers to ME/CFS: Leonard Jason, PhD** DePaul University; Chicago, Illinois, USA

## PROVOCATION STUDIES 1

**Ventilatory Functioning During Serial Cardiopulmonary Exercise Testing in People With and Without Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Todd Davenport, DPT, MPH** University of the Pacific; Stockton, CA, USA cago, Illinois, USA

## IMMUNOLOGY

**Predictors for Developing Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Following Infectious Mononucleosis: Leonard Jason, PhD** DePaul University; Chicago, Illinois, USA

## NEUROLOGY/ EPIDEMIOLOGY

**Cognitive Assessment in Patients with and without Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): Gudrun Lange, PhD** New York, NY USA

## CLINICAL CASES

**Case Presentation: Treating ME/CFS with Apripazole: Hector Bonilla, MD** Stanford University; Stanford, CA, USA

More information and further reports can be found on our website: <https://tinyurl.com/9n9fumhe> ■

# Heart-Rate Monitoring in ME/CFS

Many people with ME are now using heart-rate monitors to more accurately pace their daily activity and monitor their body's responses to exertion.

Physios 4 ME are conducting an international survey of experiences and attitudes towards Pacing using a heart-rate monitor. People with ME/CFS often use heart-rate monitors to help pace their activities. However, there has been very little research exploring the use and peoples experiences of this approach.

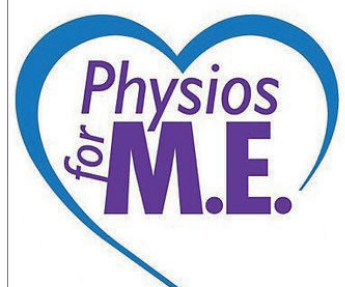
The aim of this study is to explore the experiences of and attitudes towards pacing with a heart-rate monitor (HRM) in people with ME/CFS.

The survey has 40 questions, virtually all with tick boxes to make the questions easier to answer. There are also some free text boxes to add in some extra information about your experience of HRM.

There is an email address at the end so you can contact the researcher if they are happy to be interviewed about their experience of HRM.

More details can be found on this research here:

<https://tinyurl.com/e5wfubna>





*Dr Charles  
Shepherd, Hon.  
Medical Adviser for  
the ME Association,  
discusses:*



## Anxiety and Panic Attacks

### What are anxiety and panic attacks?

Anxiety is an adaptive emotional and physical response to situations where we feel worried about something that may happen. Panic attacks are the sudden and often intense reaction to fear or anxiety that can trigger specific physical reactions in the body. The symptoms can feel very frightening whilst being experienced but they are not dangerous.

The difference between normal levels of anxiety and when to seek additional support is when the symptoms of the anxiety are impacting you living your daily life and causing significant amounts of distress to you.

### What causes an anxiety or panic attack?

In order to understand the workings of anxiety and panic, we need to understand what happens in our brains.

The part of our brain that deals with the body's automatic responses (e.g. heart, lungs etc.) gets activated when we perceive danger. This results in stress hormones, like adrenaline and cortisol, being

released which can increase for example our heart rate, breathing pattern and pupils becoming dilated. As our brain focuses its attention on its survival mechanism, it impedes the front part of the brain that deals with decision-making, cognitive flexibility and problem solving.

### What happens to me when I feel anxious or have a panic attack?

If we imagine the brain like a fire-alarm system. Any time we perceive a threat, the fire alarm system (autonomic nervous system) gets activated. The body reacts as if there were a fire occurring in the here-and-now so that it can keep you safe. What we need our brain to understand is that it reacted to the threat of a fire not an actual fire.

### What symptoms might I experience when I am feeling very anxious?

Anxiety can produce a wide range of physical and psychological symptoms. More common ones include:

- General restlessness or irritability
- Feelings of apprehension or inner tension

- Difficulty sleeping
- Increased sensitivity to physical sensations
- Dizziness
- Dry mouth
- Difficulty swallowing
- Irritable bowels
- Nausea
- Numbness and tingling
- Palpitations
- Urinary frequency

### What are the symptoms of a panic attacks?

Panic attacks are the intense reactions that can occur sometimes lasting between five and 20 minutes but this may vary for individuals.

The main symptoms are:

- Palpitations
- Shortness of breath or hyperventilation/over-breathing
- Chest pain or tightness in the chest
- Sweating
- Dizziness or feeling faint
- Numbness or tingling
- Muscular weakness – 'legs turning to jelly'
- A (temporary) effect on your eyesight

- Unpleasant feelings of unreality

### Does it help to know what is happening to your body when you are anxious or having a panic attack?

Experiencing anxiety or panic attacks can be scary if we don't understand or know what's going on as it leaves us with a feeling of uncertainty and feeling out of control. So, yes, it does help knowing what is happening in the body because once we are aware of what is happening we can then decide what might be needed to help us.

### What can we do then?

Going back to the fire alarm analogy, we want to get to a place where our brain is able to recognise the difference between a false alarm and an actual fire. We don't want to completely eliminate anxiety because if there were an actual fire, we want the system to get activated to get us to a place of safety. Rather, we want the brain to distinguish between its reaction to a hypothetical situation and a situation that requires action in the here-and-now.

### So what I am thinking about is important?

Yes it is important. How we perceive a situation can influence



how our body responds and vice versa.

### What's the first thing I can do when experiencing anxiety or panic attacks?

As we mentioned earlier on, when our automatic nervous system gets activated it impedes the part of the brain that can make decisions and problem solving. In order to reactive this system, we want to bring our stress hormones down so that we can more clearly. The simplest way of doing that is focusing on our breathing. By regulating our breathing, it will then inform our body that we are not in any danger and therefore slow our heart rate, release muscle tension and generally reduce any physical symptoms that are associated with the body's built-in survival mechanism.

### What do you mean by focusing on your breathing?

If you have a paper bag around, breathe into a paper bag. This will slow your breathing down in order for it to become more regulated. As you may recall, when feeling anxious your breathing might have been in a state of hyperventilation.

If you don't have a paper bag nearby then you can inhale for three counts and exhale for four counts. By making sure you exhale for longer than you inhale it will help relax the body. If you have a family member or friend nearby you can also elicit their help in breathing/counting with you.

### Does muscle relaxation help?

Yes it does. We need to relax and to release the tension that has built up in our muscles. Doing muscle relaxation daily will bring down the level of

anxiety so desensitising the body.

There are several muscle relaxation tapes available many of which include breathing techniques as well. Most of them suggest that you tense your muscles and then relax them, working through all the muscle groups in your body one at a time.

Once relaxation is achieved it will be more difficult for the anxiety level to rise and trigger an adrenaline rush. This, in turn, gives you time, when you feel the first feelings of uneasiness, to start to relax and to use your breathing and muscle-relaxation techniques. This will stop the adrenaline from rising into a full-blown anxiety or panic attack.

We do appreciate, however, that many people with ME cannot tense and relax muscles without feeling pain. It is perhaps a good idea not to use this form of relaxation if your muscles are painful or weak.

### Are there other ways to relax?

■ There are tapes available that play lovely music, bird song or the sound of waves lapping the shore. Although such tapes will not in themselves help you to achieve muscle relaxation in the same way as the 'tense / relax' tapes we described above, you will hopefully learn the feeling of relaxation and the difference between this feeling and the pain and discomfort of tense muscles.

■ You may even like to talk to yourself a little. For example you could try repeating to yourself several times "Calm yourself, relax". You may find a

phrase that works well for you. Feel the muscle tension go and be aware of this.

■ Breathing techniques can really help. Hyperventilation can be part of a panic attack or even an attempt to stop it. Learning breathing techniques will do two things. Breathing correctly will help you breathe steadily and calmly thus avoiding hyperventilation. Good breathing techniques will also allow you time to work through your 'uneasiness' by breathing from the diaphragm slowly and evenly until the pre-panic feelings subside.

Whatever you do to learn to relax, just remember that your aim is to bring your anxiety levels down.

The way you learn to relax must become a daily habit, like cleaning your teeth. It is no good doing this in a haphazard fashion, simply because it won't work!

### What thoughts can we offer you?

■ If you think about it, anxiety sufferers are, on the whole, intelligent people with great powers of imagination. This can be channelled to help them recover.

■ If we can remember that the first panic or anxiety attack occurs for a reason but the second and subsequent attacks do not – this can help. Someone called Jerry Augustine said: "The body manifests what the mind harbours." Remember what we said about the thinking part of the brain and the nervous system – and think about this.

■ If we can believe that an anxiety attack or a panic attack is just adrenaline accompanied by a

collection of symptoms that cannot, and will not, harm us – then we can improve.

### What else can I do to reduce my anxiety?

■ It will help if you cut down on caffeine-containing drinks such as tea, coffee and cola because caffeine stimulates the nervous system as well.

■ Take care with over-the-counter medication, especially cold remedies as some of these drugs cause nervous stimulation as a side-effect. (Check with your doctor or pharmacist before taking these).

For extra support, visit **Anxiety UK**. They run a daytime information line. You can also visit the **NHS UK** website <https://tinyurl.com/pp552998> for more information.

### What help can I get?

As medication may help some people, please discuss this with your GP. But drug treatment won't succeed on its own. A combination of professional help and self-help will be needed.

### No Panic charity

Breathing exercises and relaxation exercises can help. This is where **No Panic** comes into its own. Trained volunteers there can help with some breathing exercises and will be able to talk with you about relaxation tapes.

**No Panic** offers recovery groups via a teleconferencing system that allows you to participate in a 12-week course using layperson cognitive/behaviour therapy and anxiety management as the basis for recovery. A membership fee is required for these groups.

## ANXIETY AND PANIC ATTACKS

Talk therapy can help. Do use the **No Panic** helpline (0300 772 9844) where all the volunteers are trained to help people who are anxious or panicky. After 10pm, the helpline plays a recording of a really useful breathing and relaxation technique.

**No Panic** also has a range of leaflets you may like to read. Here's the link to their bookshop: <https://nopic.org.uk/product-category/book/>

If you have tried some of the above coping strategies and you feel that this is still having a significant impact on your daily life, then you can seek psychological support either through the NHS or privately. Please see our Counselling leaflet for more information on how to access counselling.

### When should I see my doctor?

**Our medical adviser, Dr Charles Shepherd, writes:**

If you are having panic attacks, or your anxiety levels are becoming more than just an occasional inconvenience that is not being improved by self-help management, you ought to see your GP.

In addition to all the self-help strategies that have already been covered, your GP can:

Check to make sure there isn't an underlying medical problem such as an overactive thyroid gland, or periodic episodes of low blood sugar, which can also produce anxiety-type symptoms.

Refer you for help, possibly in the form of cognitive behaviour therapy, from either a community or hospital-based

mental health professional.

Consider whether the use of one of the following anxiety-reducing drugs may be appropriate.

Benzodiazepines like diazepam/Valium are sometimes used as a rapid short-term treatment for more severe anxiety. But they can cause dependence - so extra caution is required. They are not a long-term solution.

Selective serotonin reuptake inhibitor (SSRI) drugs such as fluoxetine and sertraline are the first choice medication for anxiety disorders. They can also help where anxiety is combined with depression. However, SSRI drugs have side-effects such as insomnia, dizziness, nausea, blurred vision, loss of appetite and sexual dysfunction and they produce discontinuation symptoms if stopped abruptly. They also know that people with ME/CFS are often more sensitive to SSRI drugs. So it's normally sensible to start with a low dose and increase gradually. It takes two to four weeks before the full therapeutic effect occurs.

Monoamine oxidase inhibitors such as phenelzine are an effective treatment for panic disorder. However, they are rarely used because of diet-related restrictions, side-effects and drug interactions.

Beta-blockers such as propranolol may help with short-term symptomatic relief, especially for palpitations and rapid pulse rates. They can also be helpful in performance-related anxiety, such as social phobia.

Pregabalin (Lyrica) can be used for both acute anxiety and the prevention of relapse in generalised anxiety disorder. It can also be effective in relieving depressive symptoms, reducing pain and improving sleep.

Buspirone (Buspar) is sometimes used as an add on to pre-existing drug treatment for generalised anxiety disorder. It is not an effective treatment for panic disorder.

### And finally...

You don't need to live with intense levels of anxiety and panic as there are plenty of self-help and additional resources for support out there. ■



### ANXIETY AND PANIC ATTACKS

This new leaflet is now available from the ME Association's website shop: <https://meassociation.org.uk/product/anxiety-and-panic-attacks-questions-answered/>

If you feel your patient would benefit from reading of our other leaflets and booklets, please offer them this link: <https://meassociation.org.uk/me-association-shop/>

## ME/CFS Mental Health Literature



### COUNSELLING- YOUR QUESTIONS ANSWERED

Dr Lisa Dvorjetz reviews counselling and how it can help should an independent professional be needed to work through the understandable mental health problems that can arise from living with ME/CFS or from caring for someone with the condition: <https://meassociation.org.uk/product/counselling-your-questions-answered/>



### MANAGING YOUR EMOTIONS

Currently being updated: <https://tinyurl.com/z258cstc/>

These questions were submitted to **Dr Charles Shepherd** by ME Association members and feature within the 'Ask the Doctor' section of our Winter 2021 members' magazine, ME Essential.



## Ask the Doctor

### NEW SYMPTOMS – WHEN SHOULD I SEE MY GP?

I know that, in addition to all the classic diagnostic symptoms of ME, there are a considerable number of other symptoms that can sometimes occur.

But should we always go and see our GP every time a new symptom appears? Or when an existing symptom changes character or gets significantly worse?

In my case, after several years of having ME, I've now developed intermittent joint pains (without any swelling or redness) and bowel symptoms (mainly loose motions with occasional stomach cramps and bloating) that seem like irritable bowel syndrome.

I haven't yet mentioned these symptoms to my new GP - who tends to blame everything on ME!

I don't want to be seen as a hypochondriac, turning up at the doctors every time I don't feel well. At the same time, I don't want to find that a new and treatable medical condition is being missed.

#### Dr Shepherd says...

It is always a good idea to speak to your GP if/when a new symptom - affecting either physical health or mental health - develops during the course of ME/CFS, even if the

symptom is one that is often reported in ME/CFS.

This is because it's quite possible that a new symptom is being caused by a completely different condition, possibly one that has symptoms that are also present in ME/CFS.

For example, an overactive thyroid gland (thyrotoxicosis) can cause fatigue, sweating and palpitations. An underactive thyroid gland (hypothyroidism) can cause fatigue, constipation, increased sensitivity to the cold and cognitive dysfunction. These are all symptoms that can appear in the course of ME/CFS.

In the case of new onset joint pains it's important to make sure this isn't being caused by something like rheumatoid arthritis or lupus (SLE). There are very sensitive immunological blood tests that can help with making a diagnosis here.

And although symptoms of irritable bowel syndrome (IBS) are very common in ME/CFS, it's also important to check that these aren't being caused by conditions like coeliac disease or an inflammatory bowel disease (IBD). As with joint pains and rheumatoid arthritis, there is a simple screening test for coeliac disease. So in the case of new-onset bowel symptoms it's worth checking

for inflammatory markers (i.e ESR and CRP blood tests) and a screening blood test for IBD called calprotectin.

Please go back to your doctor if these new symptoms continue, or get worse, because they do need to be properly assessed and investigated. You may need to be referred to a rheumatology or gastroenterology specialist if there is still uncertainty about the cause.

■ The MEA has an information leaflet covering the diagnosis of IBS and the management of individual IBS symptoms in relation to ME/CFS. Visit the website shop:

<https://meassociation.org.uk/me-association-shop/>

### HOW CAN I KEEP MY HEART HEALTHY WHEN I CANNOT EXERCISE

Can I ask what the advice is on heart health for people with ME? As most of us can't exercise, how do we maintain a healthy cardiovascular system? Is a healthy diet enough?

#### Dr Shepherd says...

That's a really good question because regular aerobic/oxygen-requiring exercise such as brisk walking, running or cycling is one of the most important ways of improving your circulation and

keeping your heart healthy. But this type of exercise isn't something that someone with ME/CFS can consider until they have made a significant and sustained degree of improvement.

Having said that there are plenty of things that everyone with ME/CFS can do to try and keep their hearts healthy:

■ Have your blood pressure checked. If this is significantly elevated (= hypertension) there are drugs that can help to bring it back to a more normal level. Having a blood pressure check is particularly important if there is any family history of heart disease. However, it's worth noting that low blood pressure (= hypotension) sometimes occurs in ME/CFS and this is generally regarded to be good for heart health - even though it may exacerbate orthostatic intolerance (= difficulty in remaining standing) and cause symptoms such as feeling faint on standing up

■ Have your blood cholesterol level checked and, if it is raised, bring it down with a low-fat diet and possibly a cholesterol-lowering drug. However, care needs to be taken with the use of cholesterol-lowering drugs called statins - as these drugs can cause muscle damage as a side-effect



## ANXIETY AND PANIC ATTACKS

■ Stop smoking

■ Avoid drinking alcohol to excess - this should not be a problem if you have ME/CFS because alcohol intolerance is a common symptom in ME/CFS

■ Reduce your intake of caffeine-containing drinks - because caffeine can trigger palpitations and heart-rhythm disturbances

■ Have a well-balanced healthy diet that contains plenty of fruit and vegetables. Eat more fibre from a variety of sources - wholemeal bread, bran, oats, potatoes with skins on - and at least one portion of oily fish, which is rich in Omega-3 fatty acids, each week. Or you could take an Omega-3 supplement. Eat less fat and switch to lower-fat dairy products. Salt intake should be no more than 6gms a day - unless this forms part of the management of low blood pressure. NB: Increasing fibre intake can increase irritable bowel symptoms - so this may not be an option for everyone.

■ Lose weight if necessary

■ Look after your teeth and gums with regular dental checks - as there is evidence that chronic gum disease (i.e. sore swollen gums) is a risk factor for heart disease

■ Deal with stress - if this is occurring

If you do experience any symptoms that suggest the possibility of heart disease - chest pains on exertion, palpitations, ankle swelling - please see your GP who can carry out a basic heart examination and arrange for some heart-monitoring (ECG) tests if necessary.

Guidance on diet and heart disease from the British Heart Foundation: <https://tinyurl.com/n4cay73e>

### DO I NEED TO WORRY ABOUT MY PALPITATIONS?

Like many people with ME I have occasional palpitations. Does this mean that I might have some form of underlying heart disease? Or is this just another part of having ME? And are there any drug treatments that might be helpful?

#### Dr Shepherd says...

Palpitations are a medical term to describe having an increased awareness of your heart beating. They are very common, occur in perfectly healthy people, and in most cases are nothing to worry about.

But palpitations can be a sign of an underlying health problem. In addition to heart disease they can be caused by anxiety and stress, alcohol, anaemia, having an overactive thyroid gland (thyrotoxicosis), infections, the menopause and taking too many caffeine-containing drinks.

A number of drugs can also cause palpitations as a side-effect. Common ones include over-the-counter cold remedies, thyroxine and tricyclic antidepressants such as amitriptyline.

In the case of ME they can be caused by overactivity of what is called the autonomic nervous system - a part of the nervous system with control centres in the brain that send messages to the heart, bladder

and bowel to either speed up or slow down activity.

Having autonomic nervous system overactivity does not mean that people with ME/CFS have heart disease - the problem lies with overactivity of nerves that control pulse rate and blood pressure - not the heart itself.

If you are having palpitations it's worth speaking to your GP - especially if there is any past history or family history of heart disease or 'red flag' symptoms such as chest pains, fainting episodes or shortness of breath.

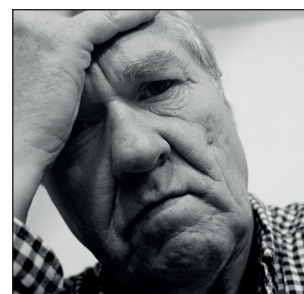
Your GP can take a proper history, examine your heart and do some blood tests to check for anaemia, thyroid function etc and, if necessary, arrange for an electrocardiogram (ECG) and ambulatory 24-hour heart monitoring to check for abnormal heart rhythms.

If there isn't any obvious medical cause, and palpitations are causing distress, there are a number of drug treatment options, including what are called beta blockers, which can slow down the heart rate. These options can be discussed with your GP.

■ The MEA has information leaflets on Anxiety and Postural Orthostatic Tachycardia Syndrome/POTS - two conditions that can occur in ME/CFS and where palpitations may also occur.

### REACTIVATED VIRAL INFECTIONS IN LONG COVID AND ME/CFS

I've been reading some interesting new research which



indicates that reactivation of viruses that lay dormant in the body after the initial infection could be a cause of Long Covid. The reasoning seems to be that Covid infection activates the body's immune system and this results in the reactivation of viruses that have been lying dormant and harmless in the body but now become active again and are capable of causing symptoms. Given the overlaps between Long Covid and ME could this be happening here as well? And has any research been done into this in ME?

#### Dr Shepherd says...

I suspect you are referring to the research that has examined the possible role of reactivated Epstein Barr Virus (EBV) infection in people with Long Covid - where two recent studies (1,2) have found evidence of EBV reactivation. As you correctly point out, these viruses could then be playing a role in causing some of the symptoms in Long Covid.

Epstein Barr Virus is the infection that causes glandular fever - so it's an infection that many people have had as a child or teenager. Glandular fever is also a well recognised trigger factor for developing prolonged post-viral fatigue and ME/CFS, especially in children and teenagers.

EBV belongs to a family of viruses called human herpes viruses - where it is classified as HHV-4. All these viruses can lay dormant after the initial infection but then reactivate in later life to cause other health problems. One fairly common example here is reactivation of the chickenpox virus to cause shingles in later life.

As far as ME/CFS is concerned, this observation is nothing new and quite a lot of research has been carried out over the years into the role of reactivated viral infection, especially with human herpes virus infections. However, the results have not always been consistent. The ME Biobank, which is funded by the MEA, has done a lot of this research and recently published results which indicate that looking for evidence of the past immune response to different human herpes virus infections can help to sub group people with ME/CFS (3).

If this type of research does demonstrate that reactivated viral infection plays a role in causing symptoms in both Long Covid and ME/CFS, then it would support clinical trials to assess the use of antiviral drug treatment. It also raises the question of whether we should be developing a vaccine to prevent some of these infections, especially EBV.

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<https://tinyurl.com/rcczjvhu>

2: Gold JE et al. Investigation of Long COVID Prevalence and Its Relationship to Epstein-Barr Virus Reactivation. Pathogens 2021 Jun; 10(6): 763. Published online 2021, Jun 17.

<https://tinyurl.com/zxetutac>

3: Herpes viruses Serology Distinguishes Different Subgroups of Patients From the United Kingdom Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Biobank. Frontiers in Medicine Med 2021, July 5.

<https://tinyurl.com/m7k8xuac>

## COENZYME Q10 – DOES IT WORK?

My nutritionist has advised me to start taking a supplement called coenzyme Q10 (CoQ10) which, she says, will boost my energy levels and improve my memory problems. What is CoQ10 and is this claim justified? Are there any side-effects? Can I take it with prescription-only medicines?

#### Dr Shepherd says...

Coenzyme Q10 (CoQ10), which is also known as ubiquinone, is often referred to as a vitamin. However, this isn't strictly true as it is made in the liver from an amino acid called tyrosine. CoQ10 is also present in a wide variety of foods. So deficiency can occur as a result of reduced dietary intake, decreased production, or increased usage - or a combination of all three.

CoQ10 is known as a coenzyme because it helps other enzymes in the body to carry out their normal

functions. In relation to muscle fatigue, it is involved in energy-producing chemical pathways inside the mitochondria - parts of the cell where energy in the form of a chemical called ATP is produced. It also has an antioxidant effect. So there are clearly some theoretical reasons why CoQ10 might be helpful in ME/CFS.

Despite all the claims being made for CoQ10 there is very little scientific evidence linking deficiency with disease in relation to ME/CFS.

There has been one small clinical trial carried out in Spain (1) to assess the use of CoQ10 in ME/CFS. This was an 8-week randomised, double-blind, placebo-controlled trial involving 73 people with ME/CFS who were given either a placebo or oral CoQ10 (200mg per day) and another supplement called NADH (20 mg per day). Those receiving the combination reported a decrease in fatigue levels and beneficial changes in biochemical markers in the blood. These results need to be viewed with caution in view of the fact that the trial involved two supplements and the follow-up period was very short. Neither is there much evidence of benefit in other diseases where CoQ10 is sometimes recommended such as heart failure, mitochondrial muscle diseases, and Parkinson's disease (where decreased levels have been found in the spinal fluid).

As far as side-effects are concerned, CoQ10 is normally well tolerated with no serious

side-effects being reported. But it has not been properly assessed in pregnancy.

One important note of caution relates to its use with statins - prescription-only drugs used for lowering blood cholesterol levels. Statins can lower the levels of CoQ10, and it has been suggested that this could make people more liable to develop statin-induced myopathy (muscle damage). This is a well recognised side-effect of statins, and is something that is occasionally reported by people with ME/CFS. So there may be a case for taking CoQ10 if you have ME/CFS and are also taking a statin (2). It has also been reported that CoQ10 can interfere with anticoagulants (blood-thinning drugs such as warfarin) at high doses.

Overall, CoQ10 is a supplement that may be worth a try - bearing in mind that reports of benefit are highly speculative rather than scientifically proven.

#### References:

1: Castro-Marrero J et al. Does Oral Coenzyme Q10 Plus NADH Supplementation Improve Fatigue and Biochemical Parameters in Chronic Fatigue Syndrome?

Antioxidants and Redox Signaling. 2015 Mar 10; 22(8): 679–685.

<https://tinyurl.com/ybs94jzf>

2: Should patients on statins take Coenzyme Q10 supplementation to reduce the risk of statin-induced myopathy?

<https://tinyurl.com/jzx3f4ak>

## EXPERT VIEW

# The pathology of central fatigue in neurological disorders

by Dr Abhijit Chaudhuri

In this Expert View, Dr Abhijit Chaudhuri discusses central fatigue in neurological disorders and proposes a model to help understand the cause of this type of fatigue and the development of new treatments.

Dr Chaudhuri advises the ME Association on clinical and research issues relating to the neurology of ME/CFS and assists with the preparation of the MEA Clinical and Research Guide (our 'Purple Book'). He trained with Professor Peter Behan at the Institute of Neurological Sciences in Glasgow and worked with Professor Leslie Findley when he was at Queens Hospital in Romford.

## The pathology of central fatigue in neurological disorders

Fatigue is a common yet poorly understood symptom in neurological disorders. Multiple sclerosis and Parkinsonian disorders are two common examples of disorders of the central nervous system in which fatigue is frequently reported (1).

Fatigue is physical as well as cognitive, and cognitive fatigue is characterised by reduced speed of registration, retrieval, and processing of information.

The level of fatigue in a patient is never uniform; variability can be induced by changes

in physical health, sleep, medications, mood, and pain level.

Chronic fatigue, like chronic pain, is a multimodal symptom, and is distinguishable from the focal or segmental fatigue of muscle or neuromuscular junction disorders which primarily involve a failure to sustain voluntary motor function.

Despite some overlap, a clear distinction should be made between 'central' and 'peripheral' fatigue (1).

To read the complete article go to: <https://tinyurl.com/h7fbxhve>. Please note you will have to register your details to do so, but registration is free. Published by Neurodiem on 04 October 2021.

## The pathophysiological and neuroanatomical processes of central fatigue

Disruptions in the process of activation in the pathways interconnecting the basal ganglia, thalamus, limbic system, and higher cortical centre are implicated in the pathophysiological process of central fatigue (2).

A state of relative hypocortisolaemia might sensitise the hypothalamic-pituitary-adrenal axis to the development of persistent central fatigue after acute or prolonged stress, of which central fatigue in patients



after viral infection (post-viral fatigue) or severe physical trauma (post-traumatic stress disorder) are possible examples (2).

Long COVID-19, estimated to affect 1.5% of UK population following exposure to the novel coronavirus (SARS CoV2) in the ongoing pandemic, bears close resemblance to the post-viral fatigue that the survivors had following the Spanish 1918 'flu pandemic' (3).

The most severe of these cases were diagnosed as 'encephalitis lethargica'. Sclerosis of the substantia nigra with occasional globus pallidus involvement was the pathological hallmark in post-mortem studies of these patients (4).

Despite an initial response to levodopa, the therapeutic benefit waned rapidly, and patients became severely dyskinetic on levodopa dose escalation.

Despite a wealth of neuroanatomical and neuropathological evidence supporting the notion of basal ganglia involvement in central fatigue, dopaminergic therapy – primarily targeting striatal dopaminergic receptors – has been less than rewarding (1).

More important, these have been few functional

imaging studies mapping the dopaminergic system in the brains of patients with central fatigue and none are yet planned for long COVID-19.

Cerebral dopamine transporter single-photon emission computed tomography (DAT-SPECT) scans are abnormal in Parkinson's disease and Parkinson-plus syndromes, confirming a reduction of presynaptic dopamine receptor transporter protein (5).

These scans appear normal in post-encephalitic parkinsonism, and nearly normal in post-viral fatigue. Patients with post-viral fatigue may show abnormalities in proton (1H) magnetic resonance spectroscopy of the basal ganglia (6).

Anxiety and depression, which are common in patients with central fatigue have been the biggest confounders in the scientific interpretation of central fatigue. Antidepressants, such as selective serotonin reuptake inhibitors or serotonin-norepinephrine reuptake inhibitors, do improve motivation, though antidepressants are not effective treatments for fatigue (1).

The development of lethargy and apathy after deep brain stimulation of the subthalamic nucleus can negate the benefits of motor improvement on the quality of life of patients with Parkinson's disease (7).

Management of mood disorders, together with pain control, remains a key clinical strategy and therapeutic priority for symptomatic patients with central fatigue (8).



## Adenosine receptors in the basal ganglia

Stimulation of the direct corticostriatal pathway in the basal ganglia results in motor activation, whereas activation of the indirect pathway produces motor inhibition (2). Dopamine, or dopamine agonists, will induce motor activation by activating the direct pathways via dopamine receptor 1 (D1) receptors.

The indirect pathway consists of gamma-aminobutyric acid (GABA)-ergic enkephalinergic neurons, which connect the striatum with GABAergic neurons in the external segment of the globus pallidus, that project to glutamatergic neurons in the subthalamic nucleus connecting to the output structures.

This indirect pathway has been implicated in motor fluctuations and dyskinesia in Parkinson's disease (8).

Adenosine A2A receptors are selectively localised on medium spiny neurons of the indirect output pathway in the basal ganglia circuit, projecting from the striatum to the external globus pallidus.

Striatal A2A receptors are expressed on pre-synaptic glutamatergic terminals of cortico-limbic-striatal and thalamo-striatal pathways, co-localising with and antagonising dopaminergic D2 receptors, and are thus integral to the basal ganglia's control of movement, motor learning, motivation, and reward (9).

Unlike dopamine, which is an extrinsic signal for neurons

in the nigrostriatal network, adenosine is an intrinsic signal locally produced from the activity of striatal circuits. Dephosphorylation of intracellular ATP generates adenosine, which is also released extracellularly from neurotransmitter synaptic vesicles and glial cells. A2A receptor antagonism improves motor function and fatigue (9).

Caffeine blocks adenosine receptors, which are the target of methylxanthines which also include theophylline. Since the late 1990s, it has been noted that using A2A antagonists with a preferential D2 agonist can improve motor function in Parkinson's disease. Istradefylline, a selective A2A antagonist, has been shown to improve fatigue (10) and mood (11) in clinical studies of patients with Parkinson's disease.

### Take-home message

Despite its shortcomings, this proposed model of central fatigue, basal ganglia and Parkinson's disease remains a useful tool for understanding and evaluating new treatment options.

In addition to dopamine and adenosine, striatal GABAergic neurotransmission will be a key area on which to focus future research since several non-motor symptoms of Parkinson's disease are dopamine-independent and influenced by GABAergic neurotransmission.

For instance, there is a reduction of GABAergic transmission in the frontostriatal circuit in Parkinson's disease and patients experiencing visual

hallucinations have reduced GABA levels in the visual cortex (12).

A centrally active A2A receptor antagonist, in combination with a GABA-mimetic drug such as gabapentin and pregabalin, which may additionally help with the control of central pain frequently associated with chronic fatigue (9), would seem a possible way forward, but large-scale clinical trials are clearly needed.

To read the complete article, visit <https://tummyurl.com/ba2udyb9> (highlighting it in blue) Please note you will have to register your details to do so, but registration is free. Published by Neurodiem on 04 October 2021.

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## Surviving M.E.

*by Russell Fleming, Communications Manager, ME Association*

**Back in the summer I was delighted to be asked to write a blog on my personal experience with ME/CFS for the Cabinet Office Disability Unit and I thought you might like to read about the improvements that I have been able to enjoy, especially as we enter the holiday season.**

**M**y name is Russell Fleming. I am 52 years old and recently began working full-time from home on a flexible basis as Communications Manager for the ME Association (MEA). I had previously volunteered for the charity and then worked part-time after being involved with them for over ten years.

The MEA is a relatively small medical charity but one that always manages to punch above its weight, providing information and vital support to people with myalgic encephalomyelitis (ME/CFS) in the UK. It also campaigns, conducts medical education initiatives, and invests in biomedical research.

### Improvements

I am in a fortunate position despite it taking me so long to reach this point. I have finally been able to accept, adapt, and accommodate ME/CFS, but it took 22 years, a lot of heartache, and many false-dawns, before my symptoms began to stabilise and then slowly improve and I could once

again feel more confident in my abilities.

Last year I moved into my first real home (albeit a rented one) and have benefitted greatly from having a garden. The lift to my spirits has been both welcome and unexpected. I had always wanted to own a dog and be able to care for him myself. It's still a work in progress, but 'Buster' is proving to be a good companion and has made me realise just how alone I had become. He is now four months old and has brought a lot of joy back into my life.

In terms of symptoms, it is my cognitive function that has improved the most. I have learned to use prompts, reminders, and alarms to aid memory. I still can't read for long and I have to limit the time spent on certain tasks – like when and how I attend virtual meetings – but for the most part I have learnt to manage it well and it is this improvement that has allowed a return to work.

I find that listening and remaining focused are still challenging and I take more time to write well, spell correctly, or to speak clearly, but working online for the most part and using a computer is helpful.

### Restrictions

I am still restricted in what I can accomplish, how long I can work without a rest, and the kind of work I can do, but I feel very lucky to have gotten this far



and to have an employer who understands.

Mobility remains a problem and I can't walk very far or climb the stairs without support. Taking a shower or washing my hair is a challenge and I average a shower a fortnight, relying on 'bed-bath wipes' (which can be heated in a microwave) for body-washes in between.

I still experience disturbed sleep with night-terrors, vivid dreams, fevered sweats, and I wake feeling unrefreshed – usually after only a few hours. I went through a particularly bad few years more recently when I was frequently urinating while asleep – that led to a big increase in laundry – and while this is a part of my life now, it has also improved.

I need to rest and sleep several times a day when the exhaustion or other symptoms become too much. I tend to start work early in the morning, when sleep has evaded me, and if my head is clear, then finish before lunchtime or when I can't do anymore.

Pain is widespread and constant particularly in my muscles and head. I am easily exhausted and fatigue is ever-present. I can't regulate temperature properly and feel very hot or very cold

particularly in arms and legs. It has always felt like I have the Flu but without a runny nose and I find myself having to judge if, when, and how I can do things with the limited amount of energy available.

### Mental health

After about 10 years, there were improvements in other symptoms. The vertigo, dizziness, palpitations, nausea, diarrhoea, and poor appetite stabilised. I still can't do many household chores for myself and am unable to engage fully in social activities or go on holiday, but I have a very good support system now in place.

I had a lot of problems with mental health – depression, suicidal thoughts, attempted suicide, anxiety, panic attacks, feelings of low self-worth and inadequacy. But these improved as my physical abilities improved. I still have issues but I am coping a lot better. There will always be the spectre of relapse hanging over me, but I know what to do if things get worse for me again.

I choose to work because it gives me purpose and is rewarding. It can be very demanding, but without support I wouldn't be able to accomplish what I can or be able to help others with ME/CFS and the families who care for them. I choose to put my energy into my work and I depend on others to help me around the house with cooking, cleaning, laundry, taking me to appointments and walking Buster when I cannot.

I can only look back in this way because I have reached a position of relative stability and improvement. Many people with

ME/CFS do not. In the last two decades I have struggled a great deal, not only with crushing physical limitations, but with the mental anguish of loss, of guilt, and the frustration of having a diagnosis that has been unfairly stigmatised and for which there is no effective treatment – let alone a cure.

### How it all began

Like many, my story began with an acute viral infection. I was 30 years old and living in Jersey – having been transferred from the UK several years before. I worked for Lloyds Private Banking and was recruited from college. I was an investment manager and independent financial adviser but had also enjoyed several other roles including in marketing where I led a team on the Bank's merger with TSB.

I loved my career and was on the fast-track. I had a lot of friends, a good social life, and was physically very active. My life was a good balance and my mental health was excellent. My dreams were to continue with my travels abroad and to settle down and start a family. I believed I had a bright future.

I was conditioned to believe that viruses can be fought, that recovery might take a couple of weeks at most, but that I would always return to full-health. Chronic illness was never on my radar. I had had glandular fever at the age of 21, which meant three weeks off work, and had experienced full-blown Flu. I was sick a lot as a child. But each time I would bounce back – full of energy – to carry on with life without looking back.

In 1999 I went on holiday with friends, picked up an infection, brought it back home, spent time in hospital, and felt like

I had been poleaxed. The suddenness with which my life changed and the extent to which the illness left me physically impaired, hit my mental health especially hard.

A year later and my functional ability had not improved, I hadn't been able to return to work, and the diagnosis of a post-viral fatigue syndrome (PVFS) had become myalgic encephalomyelitis (ME/CFS).

I was traumatised. I was terribly ill and for long periods of time I couldn't leave my bed. I didn't know what was happening; I was confused, distressed, and had lost a lot of weight. It often felt like I was dying.

My family didn't know how to care for me and we received very little help from the NHS. Even when my ability to cope was at its worst and my family felt out of its depth, there was nobody around to provide practical assistance or to tell us that I might have been eligible for welfare support or care from social services.

### Struggling

Symptom-relieving drugs and antidepressants to help with pain, sleep, and mood had to be introduced slowly because they either had no effect or I was sensitive to them and the side effects. It took a long time to find something that seemed to help even if it did for a limited time. But such drugs only ever 'took the edge off' and did nothing to resolve the underlying disease process that I believe was causing most of the functional impairment.

Dealing with loss was incredibly hard. More so because I had a diagnosis that was still questioned. We also found it hard to get mental health support from the NHS but

reached out to various counsellors and psychologists over the years because I had deteriorated so much.

At no time was it suggested that my mental health was causing ME/CFS. Unfortunately, this isn't true for everyone. I had good and bad experiences with therapists but on the whole and when I was able, it was good to talk and get things off my chest with a professional. When I was physically at my worst, so was my mental health; and I have found the reverse to be true as well.

The possibility of becoming disabled was not something I had ever considered – who does? The shock of it was profound. My body no longer produced sufficient energy to allow me to function normally. I came to rely on others for my basic needs. It was degrading, and there was a lot of guilt and shame. I didn't know who I was anymore or what my purpose was in life.

I often prayed for a different diagnosis – one that was more accepted and visible. If I had been diagnosed with multiple sclerosis for example, I think I would have coped better. I might have received more acceptance from friends, work colleagues, and certain healthcare professionals. The doubt about ME/CFS only served to make my ability to cope that much harder.

Because of ME/CFS... I lost my career – but received an early pension on the grounds of ill-health. I lost my fiancée – who stuck with me as long as she could but couldn't handle my deteriorating ability to cope (I didn't blame her). I attempted suicide. I spent a fortune chasing bogus treatments. I got into debt when my income dried

up. I went bankrupt. I returned to education as a disabled student but suffered several relapses and couldn't complete my degree. I made various attempts to return to work in jobs I thought I could reasonably manage but couldn't. I became reliant on welfare benefits to survive. I had to give up my dreams of marriage, children, and owning my own home...

### Management

Modern medicine is great. I am a fan. But nobody tells you that it's fallible – least of all doctors. Chronic illness is not spoken about enough and healthcare provision is inadequate for people who struggle year after year. A long-term condition like ME/CFS can strike anyone at any time.

The symptoms I experienced in those early years felt the same as when I was infected by the virus. I felt it had caused damage. I have since learned, and this is now true of Covid-19, that 5-10% of people who contract an infection can be left chronically ill.

Yet the disbelief that people experience when describing ongoing symptoms and disability, the lack of biomedical research to try and understand why this is happening to those that it does, and the ineffective and often inappropriate management advice, continue to let us all down. That no effective treatments are available is incredibly demoralising.

The medical advice I received during those acute early years was to rest, rest, rest. It was the last thing I wanted to hear and I found it incredibly difficult doing so little, but for long periods it was all I could manage. I have come to realise that it was probably the best advice I could



## SURVIVING M.E.

have received. My body did need to heal but, aside from the few drugs that provided some relief from certain symptoms, I couldn't see how things would really improve without a treatment that tackled the underlying problem.

The stress I experienced as an investment manager was like nothing when compared to the stress I felt from being off-work and trying to cope with something I couldn't understand. I didn't want to be ill, and I definitely didn't want ME/CFS and the misunderstanding that came with it. I didn't want to depend on others. I didn't want to be stuck in bed while my life passed me by.

I don't think there was anything worse than being disabled and not knowing what was really wrong, or how to effectively fight it when everything I tried didn't work or didn't work as fast as I needed it to. It was the same for my family. All they had to go on at the time were the erroneous headlines about 'Yuppie Flu'. We coped as best we could. It was a very steep learning curve and we made many mistakes along the way.

When I felt I could, or when my frustration drove me to it, I would push myself to do more. The problem was that my ambitions were unrealistic given my change in circumstance, and whatever I did always left me in a worse state.

My brain, that wonderful organ which had accomplished so much for me in life, couldn't restart my body. It let me down and I couldn't understand how – when I was such a positive person – I was tumbling down

the rabbit hole into depression and despair.

**Myalgic encephalomyelitis**

ME/CFS affects a person's ability to function – the way they think, remember, speak, stand, walk, sleep, initiate and complete daily tasks, and generate energy. It impacts their quality of life and that of their family. Research has suggested the effects on quality of life are worse than they are for people with multiple sclerosis, cancer, diabetes, and other serious medical conditions, although in general there appears to be a similar impact on mental health.

It robs a person of the vitality I think we all take for granted which makes it especially hard to manage. It can occur suddenly, and the trigger for the majority of people is an infection that is often acute.

Trying to do too much will often result in an increase in symptom severity, even a relapse, that is typically delayed by 24 hours. One of the difficulties that doctors have with ME/CFS is that the 'great panacea' for other illnesses, namely exercise – especially aerobic exercise – can cause harm. Research has supported this phenomenon and the new NICE clinical guideline will alert doctors against recommending exercise.

Hopefully, over time symptoms will stabilise – it can be months, years, or decades – and show signs of relative improvement, which is when new activities – or an increase in the time and/or intensity spent doing an activity – might be attempted and maintained. Sometimes, these periods of stability might be fleeting, at others they can

last longer and be built upon. Full recovery is rare and even a period of stability can prove false.

Self-management techniques such as pacing – where you learn what you can do within your limitations, what tasks you can delegate or spread out across several time periods, and where you attempt to stay within your 'energy envelope' – is the safest and most effective approach at this time. It isn't an easy thing to learn. It will take time. But it is worth trying and returning to.

ME/CFS causes fluctuating symptoms, symptom severities, and functional abilities. These can vary in intensity from hour-to-hour, day-to-day, and week-to-week. Relative recovery, if it occurs, is not in a straight line, there will be many 'peaks and troughs' along the way, and some people experience an illness that progressively gets worse or shows no sign of improvement at all. It is very unpredictable.

People who are very severely affected are wholly bedbound and require 24-hour care. They can't walk or feed themselves and often can't communicate. They can lose a lot of weight and can be extremely sensitive to light, noise, touch, and smell. They are the most neglected when they should receive the most care and support.

Around 25% of people with ME/CFS are severely affected at any one time – meaning they are confined to bed by the severity of their symptoms – and perhaps 5% are very severely affected, but there is a lack of research in this area which is



shameful. Unfortunately, people have died from this condition or it has contributed to death as a result of complications and people wasting away.

If symptoms do stabilise, then a person can slowly learn to accept, adapt, and accommodate their disability. It is of course much easier said than done and can take an awfully long time, especially without good healthcare, social care, welfare, and family support.

Some people are better at acceptance and adapting than others. I resisted full acceptance for 10 years because it felt like I was giving up. I was very stubborn and didn't want to surrender my dreams but in the end I realised they were holding me back.

Had I recovered, and I hoped I would after my time at university, then I would have returned to the Bank who had given me that option. But the relapses I experienced at university finally led to me seeing sense. My old life was over and I needed to make the best of the life I had.

Ultimately I have been lucky, even after these two decades. If the physical symptoms hadn't stabilised and improved, if I hadn't been able to give it time

and be more certain of my abilities, I wouldn't have been able to return to work, move into a new home, and find a new companion in Buster.

When this illness becomes chronic it may be unreasonable to think about returning to a previous life and career. But that doesn't mean life lacks value and neither do people with ME/CFS. They are the bravest and most resilient people I have ever known and I hope they all get to experience the relative stability and improvement that I have achieved in recent years.

■ Long-term conditions are conditions that cannot be cured but can be managed through medication and/or therapy.

■ It has been estimated that over 26 million people in the UK live with a Long Term Condition (around 40% of the population), and over 10 million who live with two or more such conditions.

■ People with Long Term Conditions account for over 50% of GP appointments, 64% of all outpatient appointments, and occupy 70% of hospital beds.

■ Long Term Conditions represent a significant problem for the Government, NHS, and social care services. Research is lacking, and the solutions are inadequate (the above statistics are over five years old!).

■ ME/CFS is a neurological disease. It can affect anyone at any time of life and often becomes chronic or long-term. It is more prevalent in ethnic minority groups. Up to 70% of those affected are women. It is the biggest cause of long-term sickness absence from school.

The number of people with ME/CFS has been estimated at 265,000 in the UK (0.4% of the population). It is likely that the majority remain undiagnosed or mislabelled and receive inadequate or inappropriate care and support.

■ A new NICE clinical guideline has now been published.

It provides a framework of recommendations to the NHS and social care services and should lead to better understanding, support, and management options for people with the condition. It should also help increase early and accurate diagnosis. A network of secondary care referral (outpatient) services exist across England and with the new guideline these should be improved and extended, with similar networks established for people who live in Northern Ireland, Scotland, and Wales.

■ The ME Association provides a large range of literature about ME/CFS written by Dr Charles Shepherd (Hon. Medical Adviser) and its other expert advisers. You can view all the booklets and leaflets by visiting the website shop where they can be purchased for a small fee (or are free) and downloaded. The ME Association website provides a lot of information for free and features regular blogs on relevant news and research developments, and its social media pages (e.g., Facebook) are a great place to visit and join in discussion about life with the condition.

<https://meassociation.org.uk>

<https://www.facebook.com/meassociation/>

## Interstitial Cystitis

Urology Awareness Month was launched by the Urology Foundation in 2014 and it aims to raise awareness of urological conditions and to encourage men and women to take care of their urological health.

The Urology Foundation says:

"It is estimated that one in two of us will be affected by a urology condition in our lifetime. Our urology health is vital to our quality of life. But diseases and cancers of the kidneys, bladder, prostate and the male reproductive system are becoming more prevalent and devastating the lives of millions of men, women, and children in the UK."

Dr Shepherd says: "Bladder symptoms are quite common in ME/CFS, however, the number of people who would meet diagnostic criteria for IC is really quite small. Currently, I am not aware of any decent epidemiological studies that have provided information on the actual prevalence of IC in ME/CFS. In medical terms, IC is regarded by some (but not all doctors) as a co-morbidity in ME/CFS."

Dr Shepherd, the MEA's Honorary Medical Adviser has written a free information leaflet that is available to download for free here:

<https://tinyurl.com/zt5r96nz>

We also have a leaflet covering all aspects from irritable bowel symptoms, how to manage symptoms and considering dietary changes:

<https://tinyurl.com/ram38k7p>

The MEA is also collaborating with Bladder and Bowel Community website to help spread helpful information about bladder and bowel issues, as it is important to highlight these issues that are often taboo subjects within society.

<https://www.bladderandbowel.org>

<https://www.bladderandbowel.org>

### Bladder and Bowel offer

The Bladder and Bowel Community support the millions in the UK who are affected by a bladder or bowel condition by providing online information via their website. They work towards making a real difference to the lives of those affected by bladder and bowel control problems and delivering the kind of services that will meet the needs of those people affected by these issues.

They provide support services such as their closed Facebook support group with over 16K members, Home Delivery service for those with appliances such as a stoma or catheter and the original **Just Can't Wait** toilet card.

The **Just Can't Wait** card has been designed to allow you to discreetly indicate to someone whilst you're out that you need the toilet urgently. Please inform your patient if they need to access this.

The **Just Can't Wait** card is available for free as a Digital Card on Android or iOS smartphones or you can apply for a Plastic Card via post for a small charge: <https://tinyurl.com/4uzyfh39>

# Learn more about ME/CFS with the Online CPD Training Course!



## Myalgic Encephalomyelitis Chronic Fatigue Syndrome

StudyPRN

### TAKE THE COURSE

Take the online training course from StudyPRN

<https://www.studyprn.com/p/chronic-fatigue-syndrome>

**We want to work with Health  
Care Professionals to improve  
knowledge about ME/CFS**

**FREE RESOURCE ■ USES CLINICAL CASES  
ASSESS KNOWLEDGE OF ME/CFS**

You'll receive one hour of CPD on successful completion of the resource.

Please complete the questionnaire here:

<https://tinyurl.com/y6utwe5c>

*"Great to have a well designed, succinct but very informative and up to date course on ME/CFS. I will be forwarding the link and urging other professionals to follow this short, but excellent course."*



The CMRC <sup>1</sup> Medical Education Group is led by Dr Nina Muirhead <sup>2</sup> (an NHS surgeon with ME/CFS, pictured left), who has launched in partnership with Study PRN an accredited training module for health professionals about ME/CFS.

■ The course was produced by medical experts in ME/CFS.

#### Why take this course and who is it for?

■ The course has been designed for HCPs and anyone with a professional interest in the condition.

■ It will help you identify symptoms, determine a diagnosis and consider effective treatments using case study examples.

#### What might the benefits of taking the course be?

■ The module works with you to determine correct answers and your knowledge about ME/CFS will be improved as a result.

■ We hope HCPs will learn more about ME/CFS from this module, and that this knowledge will lead to better healthcare outcomes and improved relationships with patients.

<sup>1</sup> The CFS/ME Research Collaborative chaired by Professors Stephen Holgate and Chris Ponting.

**For more information visit:**  
<https://tinyurl.com/d6c9k3zs>

<sup>2</sup> Dr Nina Muirhead (BA (Oxon) BMBS (Oxon) MRCS DOHNS MEd PGDipDerm). Dr Muirhead is also associated with or an alumnus of: Oxford University, Open University, Cardiff University, Buckinghamshire Healthcare NHS Trust, the Royal College of Surgeons, and the Royal College of Physicians.



WWW.MEASSOCIATION.ORG.UK

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