Guildford & West Surrey

ME/CFS Support Group

Newsletter

August 2021

NICE Guideline – A New Chapter in The History of ME begins today, 18th August

ARTICLE CANCELLED

The Guildford ME Group (GMEG) newsletter team was going to cover for you in detail the contents of the new ME/CFS NICE guideline, with a special focus on the applicability to patients. However, we are dismayed to report that NICE has paused the public release of the guideline only 8 hours before its publication.

This is an unprecedented event in the long-established process of NICE guideline publication and we are hearing from multiple sources that Freedom of Information requests from ME advocates have been made regarding the derailing of the usually extremely transparent process, with various ME charities now discussing public inquiries and legal action.

Stakeholders and guideline committee members (including those belonging to NICE) were not informed of the indefinite publication pause, and only learned of it when the following statement was posted on the NICE website at 3.15pm on Tuesday 17th:

> *NICE has today (17 August 2021) taken the decision to pause publication of its updated guideline on the diagnosis and management of myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS).*
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> *The guideline recognises that ME/CFS is a complex, multi-system, chronic medical condition where there is no 'one size fits all' approach to managing symptoms. The causes of ME/CFS are still poorly understood and because of this there are strong views around the management of this debilitating condition.*
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> *Because of issues raised during the pre-publication period with the final guideline, we need to take time to consider next steps. We will hold conversations with professional and patient stakeholder groups to do this. We need to do this so that the guideline is supported.*
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> *NICE has used its usual rigorous methodology and process in developing this guideline but despite the best efforts of the committee, that followed these to the letter to bring together the available evidence and the real, lived experience and testimony of people with ME/CFS, we have not been able to produce a guideline that is supported by all.*
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> *We want to thank everyone who has contributed to this guideline and particularly the committee and the patient groups who have worked so diligently. However, unless the recommendations in the guideline are supported and implemented by professionals and the NHS, people with ME/CFS may not get the care and help they need.*
>
> *In order to have the desired impact, the recommendations must be supported by those who will implement them and NICE will now explore if this support can be achieved.*

There's sure to be plenty of media coverage about how a guideline already signed off on by all parties who were required to has been halted in this way, but if you'd like to follow things yourself, NICE is likely to post any updates here:

https://www.nice.org.uk/news/article/nice-pauses-publication-of-updated-guideline-on-diagnosis-and-management-of-me-cfs

Q&A with NICE committee members, hosted by MEAction

UNDER DISCUSSION

MEAction was due to host a community Q&A with two NICE committee members on Tuesday 24th August, described as being:

"…a chance to find out about how the guideline was developed and ask guideline committee members about their views on the recommendations that have been made. We will be joined by two of the NICE guideline committee members, Adam Lowe and Caroline Kingdon, who have spent almost 3 years working on this guideline."

At the moment MEAction is hoping to go ahead with this, so do check their website for updates (https://www.meaction.net/countries/uk/).

Further information on the panellists: Caroline Kingdon is a Research Nurse at the London School of Hygiene and Tropical Medicine, and has extensive clinical experience of ME, while Adam was one of five hard-working patient representatives who lent his energy to give a voice to sufferers. "What surprised me was the amount of consensus in the room. We agreed on so much," says Adam. "It was an honour to be part of such a thorough, transparent and professional process. Discussions were sometimes difficult, but they were always handled with mutual respect and an earnest passion for helping the people affected by ME."

If the Q&A does go ahead, you will be able to put questions to Adam and Caroline by raising your hand and speaking, typing in the chat box, or sending a question in advance to uk@meaction.net, with the event beginning at 5pm.

There are only 100 spaces to attend so register now at https://www.meaction.net/2021/08/11/chat-to-nice-me-cfs-guideline-committee-members/

Other News Snippets

- ME and Long Covid research organisation Doctors With M.E. suffered a serious cyber attack on Wednesday 14th July, “Following interaction by known antiscience proponents”. Details are currently scarce while the incident is processed by cyber crime authorities, but Doctors With M.E.’s statement can be found here:

https://doctorswith.me/cyber-security-alert-for-research-medical-and-allied-communities-working-on-me-or-long-covid/

- A misconduct complaint has been made against UK ME charity Action for ME over its historical endorsement of the PACE Trial. The complaint, submitted to the Charity Commission and Office of the Scottish Charity Regulator, claims that in endorsing the trial AfME failed to comply with the law which requires charities to act in the public interest. Sonja Chowdhury, chief executive of AfME, has responded that, while the charity was involved in the trial, “we categorically do not endorse its results”.

More can be read here: https://www.pressreader.com/uk/the-sunday-telegraph/20210725/281814286891887

GMEG’s August Articles

We hope you find the following articles, put together by our GMEG newsletter team, both interesting and useful! Energy management is still hoped to officially be at the heart of NICE guidance when it is finally released, so we hope this summary of the excellent pacing advice from the Royal College of Occupational Therapists contains good tips for both seasoned and new pacers alike. Our second article addresses an ME symptom very close to our hearts: cardiac arrhythmias. Arrhythmias are experienced by many ME sufferers, yet rarely seem to be discussed, so we hope this gives some insights on a somewhat neglected topic. Enjoy, and all the best from the team!

How to Conserve Your Energy

Newsletter editor’s note:

This is an edited and shortened version of the Royal College of Occupational Therapists (RCOT) guide, which can be found here:

https://www.rcot.co.uk/conserving-energy

The subtitle of the guide is “Practical advice for people during and after having COVID-19” but we think it’s great practical advice for post-viral illness in general, including ME/CFS, so *we're reproducing it here. It is part of a series of 3 guides that the RCOT have produced in relation to COVID-19, published May 2020. This increased recognition of the impact of post-viral illness by one of our Royal Colleges is encouraging to see.*

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When you are ill or recovering from an illness, you are likely to have less energy and feel tired. A simple task, such as putting on your shoes, can feel like hard work. This guide will help you to find ways to conserve your energy as you go about your daily tasks. By making these small changes you'll have more energy throughout the day.

The 3 Ps principle (Pace, Plan and Prioritise)

Learning to pace, plan and prioritise your daily activities will help you to save energy.

PACE

Pacing yourself will help you have enough energy to complete an activity. You'll recover faster if you work on a task until you are tired rather than exhausted. The alternative, doing something until you're exhausted, or going for the big push, means that you'll need longer to recover.

Break activities up into smaller tasks and spread them throughout the day. Build rests into your activities, it's key to recharging your energy. Plan rest breaks between activities. Sit and rest wherever possible.

PLAN

Look at the activities you normally do on a daily and weekly basis, and develop a plan for how you can spread these activities out. If certain activities make you fatigued, rather than do them in one go, plan ahead to do them throughout the day. Change the time of an activity: instead of having a bath or shower in the morning when you are busy, have one in the evening. Do weekly activities such as gardening, laundry and food shopping on different days, with rest days in between.

PRIORITISE

Some daily activities are necessary, but others aren't. Ask yourself the following questions to find out which of yours are necessary: What do I need to do today? What do I want to do today? What can be put off until another day? What can I ask someone else to do for me?

The guide is filled with practical tips for different activities of daily living, including washing, cooking and shopping. See examples below, or refer to the full guide for all 71 tips!

11 top tips:

- Sit in the shower if possible, and also when you brush your teeth and dry your hair.
- Is bathing an activity you enjoy and are willing to spend a lot of energy on?
- Is a daily bath or shower even necessary?
- Dress your lower half first when you have more energy, so as not to shock the postman.
- Find recipes with a short preparation time.
- Cook large amounts and refrigerate, or freeze extra portions.
- Buy frozen ready meals for days when you are kaput.
- Allow washing-up to air dry.
- Spread heavy activities throughout the week, for example hoovering.
- Can someone else do the heavy activities instead?
- Shop online wherever possible.

The Off-beat Heart – Arrhythmias in ME/CFS *(By Annie Kingston)*

Lying awake, heart rate climbing like elephants stampeding up a hillside...I'm not anxious or worried and, like every other day this happens, I've done no activity that should make a heart try to jump out of its rib cage in protest. A minute more and the galloping of its beat is becoming uncomfortable; a slight dizzy feeling is setting in. I'd judge it's just touched 140bpm. The raging swiftness of it is starting to make the tip of my nose tingle.

Suddenly, it stops. More than a second passes and no beat. It feels like a moment between life and death. *Now* I'm worried. Then, 'thud'...a sickeningly heavy contortion of my poor tortured cardiac muscle brings a spasmodic lurch of blood to the big vessels of neck and belly and tells me I haven't hopped the mortal coil just yet.

I catch my breath while things settle to a nice, calm rhythm of 60bpm. The elephants are at rest. It's a short-lived moment of relief, though, because after only a few seconds the inexplicable climbing of pulse begins again. It's going to do this, cycling through increasing tachycardia and a terrifyingly sudden cease in beat, for several hours. The next morning I'm exhausted and sleep deprived and spend even more of the day asleep in bed than usual.

This is a recurring memory of scary, sleepless nights spent as a teenager, a few years after my diagnosis of ME by a hospital paediatrician. It's an experience of heart arrhythmia that, in some form or another, is shared by an overwhelming majority of people with our condition.

A set of studies by Lerner *et al*[1], found that 96% of their ME/CFS participants had abnormalities in the way the heart electrically recovers after a beat in preparation for the next beat ('T-wave oscillations', for the medically initiated), a process largely controlled by the sympathetic nervous system – the same branch of the nervous system that takes a leading role in creating the fight or flight response. It's a subtle finding that is overlooked by standard ECGs.

Other studies[2,3] suggest we additionally have a tendency towards a higher overall heart rate, and also towards less heart rate variability. A heart rate that is less up and down may sound like a good thing but – importantly – it is actually very far from ideal. A healthy heart is not a metronome. It alters its rate constantly in response to very short-duration events such as breathing in and out, as well as to longer, less frequent changes such as time of day.

A normal heart has a rate that's between 9 and 24bpm slower on breathing out than on breathing in, which has knock-on effects on blood pressure, vascular tone, and a cascade of other rapidly fluctuating physiological changes. Similarly, a normal heart slows its rate by an average of 25bpm between midday and sleeping hours. These cyclical changes in rhythm are part of how the normal, healthy body goes about its daily business, and they help moderate processes such as blood flow, hormone release and cell signalling. Any rhythm that falls outside this normal functioning is an arrhythmia, and often (though not always) hints that the body is struggling to behave as it should.

Interestingly, the amount of slowing and accelerating in a patient's short duration (known as 'High Frequency') heart rate changes, such as during breathing, can be compared with the amount of slowing and accelerating in their underlying longer, circadian type ('Low Frequency') changes to give an estimate of how active the parasympathetic nervous system (very roughly, the 'calming' branch of the nervous system, which predominates at rest) is compared to the sympathetic nervous system (the branch that oversees the stress response). What's been found is that ME/CFS sufferers show less variability in the High Frequency range. This means that when our hearts should be slowing on short-term events like breathing out, they slow less than in people without disease who have a similar level of inactivity in lifestyle. Crudely put, this suggests that the sympathetic nervous system in ME/CFS is more active than it should be. I realise there'll be a long wait if I'm expecting any gasps of surprise from any of you, here.

Added to all this is the well-known finding of Postural Tachycardia, an arrhythmia in which the heart excessively increases its rate in response to standing up (estimated to be three times more common in ME/CFS patients), along with the possibly linked finding that sufferers often have reduced blood volumes that cause the heart to try to work harder to maintain blood pressure[4]. And then there's the clinically recognised ME/CFS symptom of palpitations, the term given to the sensation of being able to feel the heart's contractions more strongly than normal, which often arise as a feeling of a skipped beat or sudden lurch in the chest. They usually stem from the heart beating too early and then contracting forcefully to clear extra accumulated blood – a happening that doesn't carry the dangers of the more serious fibrillations of cardiac disease, where the heart contracts chaotically for prolonged periods with little co-ordination in timing between chambers, but is nonetheless another instance of nervous system signalling gone awry.

So, what does all of this mean for us and our illness? With overactive sympathetic nervous systems, we can expect all sorts of disruption to normal functions, and heart rate is no exception. The climbing and stopping of beat that I experienced throughout childhood had no structural cause in my physically healthy heart, and was almost certainly a manifestation of a dysfunctional grappling for balance between the two often antagonistic nervous system branches – a rate variability that, rather than being the subtle, positive one of a healthy person, was one gone to extremes. Although that particular arrhythmia is, for me, a thing of the past, several other types of abnormal rhythms have occasionally reared their heads since, including those alarming palpitations arising from intermittently early beats. However, these are only relatively benign, brief consequences of a central nervous system out of whack. With the more constant, less detectable abnormalities in rhythm that studies like the ones into T-waves, LF:HF ratios and postural tachycardia are finding, the effects may be less benign.

Because of the effect heart rate variability has on cycles in circulation, the abnormal blood flow patterns to the brain that have been observed in ME/CFS could be a result of low level but persistent problems in heart rhythm – problems which are not catastrophic, life-threatening, or damaging to the heart, but that contribute to or cause less than ideal environments in organs (like the brain) sensitive to blood flow, and keep being perpetuated by a nervous system that is not functioning as it should. The restorative processes of the brain during sleep could be particularly disrupted, potentially causing the unrefreshed feeling we get after what should have been a good night's rest.

There is a positive takeaway from the ideas thrown up by research like this. To a certain extent, the sympathetic nervous system is malleable; we might not be able to fix its bad behaviour with a few choice words, but we can be a calming influence that at least encourages it to unbend a little. It was noticed in one of the heart variability studies[4] that sufferers who took part in a session of sitting isometric yoga (a type of yoga that focuses not on movement but on holding body position) slightly improved their High Frequency rhythm abnormalities, reflecting a probable 'reining in' of the sympathetic nervous system's over-excitement and allowing a little more balance to prevail. It's no cure, of course, but management techniques like this may prove of some much-appreciated help in the ongoing battle of getting our elephants to at least slow to a trot.

Note: do please check in with your GP if you are at all worried about your heart.

Sources

1 Lerner, Goldstein, *et al.,* 'Cardiac Involvement in Patients with Chronic Fatigue Syndrome as Documented with Holter and Biopsy Data in Birmingham, Michigan, 1991-1993'. *Infectious Diseases in Clinical Practice* 6 (1997): 327-333

2 Khairunnessa Rahman, BMedSci (Hons), Alexander Burton, PhD, Sally Galbraith, PhD, Andrew Lloyd, MD, Ute Vollmer-Conna, PhD, 'Sleep-Wake Behavior in Chronic Fatigue Syndrome'. *Sleep*, Volume 34, Issue 5, 1 May 2011, Pages 671–678

3 Escorihuela, R.M., Capdevila, L., Castro, J.R. *et al.* 'Reduced heart rate variability predicts fatigue severity in individuals with chronic fatigue syndrome/myalgic encephalomyelitis'. *J Transl Med* 18**,** 4 (2020)

4 A. Hoad, G. Spickett, J. Elliott, J. Newton, 'Postural orthostatic tachycardia syndrome is an under-recognized condition in chronic fatigue syndrome'. *QJM: An International Journal of Medicine*, Volume 101, Issue 12, December 2008, Pages 961–965