

Dialogues for a neglected illness - transcript.

Activity Management –

PACING

Adequate rest and learning how to avoid triggering post-exertional malaise, is an essential management strategy in ME/CFS. It has the potential to reduce symptoms, improve quality of life and if practised early in the disease, may improve prognosis.

The new ME/CFS NICE guideline draft recognises the importance of managing activity within an individual's 'energy envelope', stating: "each person has a different and fluctuating energy limit, and they are the best judge of their own limits".

Charles Shepherd

My view is that activity management is actually the most important part of management in our current state of knowledge. What we're talking about is any kind of activity which involves energy expenditure, so that's physical activity, mental activity, and even emotional activity.. and the way you should be looking at activity management is taking into account the severity of the person's illness, it's also dependent on the stage of the illness, and the degree of variability, as to how their symptoms are varying throughout the day, from day to day and week to week. So all those factors have got to be taken into consideration when you look at activity management. And the type of activity management which I think most doctors would now agree is the best type of activity management is what we call pacing, whereby in very simple terms you are keeping, you are finding a baseline of activity, whether it's mental, physical activity that you are comfortable with, and that can be very minimal obviously, at the severe level, or it may be you know, fairly active for someone whose improving, getting better and in a milder category. So you find a baseline that you are comfortable with and then you.. in little chunks, have little, small amounts of physical , mental activity interspaced with periods of rest and relaxation... we find that some people can make progress and make some degree of improvement over a period of time. But it is very important not to push yourself beyond what you feel you can do. It's very tempting on a good day to do too much and you then end up with post-exertional malaise and then you're unable to do something the next day and it may be days and days after. So keep within your limitations, small chunks of activity, interspaced with rest and relaxation.

Energy management is: a long-term approach – it can take weeks, months or sometimes even years to reach stabilisation or to increase tolerance or activity"

NICE Guideline Draft 2020.

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“Studies show that the energy envelope approach....helps patients pace activities and manage symptoms and can significantly improve their quality of life.”

Energy conservation/envelope theory interventions - L Jason, M, Brown, A Brown, M Evans, S Flores, E Grant-Holler, M Sunnquist. Fatigue: Biomedicine, Health & Behavior 2013

Luis Nacul

It's like thinking about people have a limited energy level available to them and if they go beyond that energy envelope as some people call.. they may suffer afterwards and because the intolerance is not immediate to the effort, people tend to sometime go beyond what they should. So, it's very important that people understand this concept and pacing can be incorporated into their daily life and daily routines

If you do pacing and learn how to control your symptoms early on in the disease this may improve the prognosis.

Cardiopulmonary exercise testing of mild and moderately ill patients is used by research groups to improve understanding of exercise intolerance and post-exertional malaise in ME/CFS.

Chris Snell

If a patient can avoid bringing on symptoms of post exertional-malaise we have found that they are able to function in their daily lives much more efficiently. So you're avoiding the sickness. The key to that is adjusting your energy output, your energy expenditure to a level below that level that is going to trigger symptoms of post exertional-malaise. We've found that the most likely trigger is a point called the anaerobic threshold.

Mark VanNess

One of the more useful measures that we get from a cardiopulmonary exercise test is what we refer to as anaerobic threshold. It is a measurement that's made with gas exchange data. It cannot be reliably estimated from calculations and things like that, especially not in ME/CFS patients.

It's an exercise intensity or activity intensity that's high enough to where the aerobic energy system can't provide all the energy, the intensity is too high to rely on aerobic metabolism, and so the anaerobic generation contribution to that becomes significant.

Energy Production

Two main energy liberation systems:

Aerobic Metabolism

- oxygen dependent
- very efficient
- time intensive
- predominates at lower workloads
- CO_2 is byproduct

Anaerobic Metabolism

- no oxygen needed
- contributes more at higher workloads
- 2 ATP per glucose vs. 30-36
- Lactic acid is byproduct

- Prof Mark VanNess

So you think of the energy generation as a continuum being predominantly aerobic, and where the aerobic energy system can't maintain that energy production, anaerobic metabolism becomes significant. You can see breathing changes, metabolic differences in terms of production of lactic acid, changes in PH within the tissues, that's the beginning of the anaerobic threshold. Often times when we say, in ME/CFS patients the anaerobic threshold occurs at a lower exercise intensity, that's a description of a damaged aerobic system.

A successful pacing strategy means learning how much activity produces a post-exertional response and it can be something very benign, walking up and down stairs, standing in an upright posture to do dishes, or carrying on a conversation. And those can be above what a patient can tolerate. Learning that can be a challenge.

Todd Davenport

Any pacing programme should start with a thorough evaluation of what people are having problems with, because that then could give you an idea of the metabolic level that's causing symptoms, that you can use to base a pacing programme from. People with ME/CFS might actually underestimate the level at which they are functioning, so I think what's useful for people is to have them wear a heartrate monitor to see what level of exertion, cardiac exertion they really are putting out for various daily activities. And it can be very surprising to be at a heartrate over your anaerobic threshold sitting in a chair, taking a shower, driving into work. But I think a heartrate monitor coupled with an alarm that's set at the anaerobic threshold can be very helpful, to get people thinking about the level of exertion that's involved in their daily activities and that should form the cornerstone of a good pacing programme, So a pacing programme really should help identify their short term symptoms, kind of their precursor symptoms to a big crash. This will give them the idea of when to pull back, and when they need to rest.

So when your heart rate monitor alarm goes off, the longer you persist with your activity the more likely you are to kick in to the symptom exacerbation. So the best idea when the alarm goes off, indicating you're over your anaerobic threshold, would be to lie down and rest,

This could be rest in a face up supine position, with diaphragmatic breathing, or could be resting in a seated quiet position and the goal of the resting is to bring your heart-rate down below the anaerobic threshold and to get that alarm to turn off. How long that takes may depend on the prior activity, the severity of the condition, it can take minutes, it can take hours, it can sometimes take days, especially early on when someone's adapting to a pacing programme, getting used to it.

Formulas to estimate anaerobic threshold in healthy people are not appropriate in ME/CFS.

Prof Mark VanNess suggests a potential guideline.

Mark VanNess

Being able to learn to use a heart rate monitor effectively can improve capability and diminish symptoms. Oftentimes as the result of our exercise test, we'll know when someone's done an exercise test, what is their heart rate at the AT and so we can tell them on day one – this is your heart rate at your AT. On day two it will go down rather dramatically, but it gives them a target, something that they can respond to. So we're often asked, 'If I have not had an exercise test what should I set my heart rate monitor at?' Oftentimes people are told, incorrectly, you can use formulas to figure that out. The difficulty with formulas is they don't take into account the higher resting heart rates that ME/CFS patients tend to have or the lower max. heart rates that ME/CFS patients tend to have. In an examination of a large group of ME/CFS patients, several hundred that we've done exercise test results on, we kind of come up with a little bit of a guideline and that guideline can be used as a starting point for someone that's using a heart rate monitor to control or provide feedback for activity pacing - and that is fifteen beats per minute above the resting levels. So if you have a resting heartbeat of 85 beats per min, you should probably start out with setting your heart rate monitor to beep at 100 beats per min. to provide that feedback, so you'll know when to diminish activity, lay down, recover, allow your heart rate to come back down, before you continue that activity. And as many people know that's a very small window - a cardiovascular operating window – a very small magnitude of increase, but if people learn to constrain or restrain their activities to that, often times they'll expand their capabilities throughout the day.

Charles Shepherd

Um the trouble with all that is, that we don't have anyone in many situations who can advise these patients on how to carry this out. So there's a big need for education and training of health professionals that could have a very important input here into providing these patients with what as I say is probably the most important aspect of management at the moment, and which is just not there.

Using a heart rate monitor to help with pacing.

“Setting an alarm at a rate that is about 15 beats per min. above your resting level is a good guide to recognize when you’re over-exerting and it’s time to rest. If you have POTS, spikes in heart rate that set off the alarm may not represent over-exertion but instead, a hypotensive event. Use the feedback to correct your position.”
 Prof Mark VanNess. Oct. 2020

Activity logs, diaries, timers and heart rate monitors can all help patients understand when they are exceeding their specific energy limits, if they have enough energy to use them.

Learning to pace is a slow and challenging task and setbacks are inevitable.

Patients who know about the importance of pacing are doing the best they can, largely unsupported and sometimes disbelieved.

Grace – ME/CFS for two years.

Grace deteriorated or ‘crashed’ after several months of graded exercise therapy.

I am trying to practice pacing. I find it really difficult, um it’s been easier since I started to track my activity and how I’m feeling. Umm but it’s really difficult because things are, you know the reaction can be delayed and it’s difficult to link up why do you, what was the thing that you did before that made you feel like you do now. So I try, but I’ve got to get better at it.

So for me pacing is being aware of how much you’re doing and limiting, having a window in which to operate, and thinking ahead, so if you know you’re going to be doing something particularly strenuous then to rest in advance of that. And just keep, keep really ... um keep track of what you’re doing and also split tasks into smaller chunks, So do something for 15 mins and then lie down or sit down and then do another 15 mins. Even with my jigsaw I have to, you know, make sure I don’t do more than half an hour at a time and have a rest.

‘R’ – ME/CFS for two years.

‘R’ became bedridden after graded exercise therapy. His identity has been hidden because prejudice about ME/CFS could impact on his career.

I find that when I’m overdoing it I will not breathe properly, or regularly, or deeply enough and that is a sign that I need to pace.

One thing that can make me feel, or does make me feel worse is if my heart-rate is elevated above approximately 100 or just over 100 bpm I’m above that for a prolonged periods of time let’s say a few mins. If I persisted in that kind of behaviour, I can be pretty sure that I am going to end up in a downward spiral from that point afterwards. The degree of downward spiral does of course depend on my state prior

to that. So when I initially started monitoring my heartrate the downwards spiral was within a less well managed context, so the downward spiral was more brutal. Now the downward spirals are still extremely distinct non-the-less. Going up the stairs is something I have to be careful with. Again, now that I'm better managed, going up the stairs is less of a problem than it was, but I'm not, let's put it this way, I'm definitely not running up the stairs. I have to walk up the stairs carefully. There are times still, but less than previously, it used to be constant, where I would end up going up stairs basically on all fours because I would use less energy. And then between flights, because the stairs turn, I have a seat where I stop and allow my heart-rate to subside, which is very specifically to remain under my anaerobic threshold for as much of my existence as possible, to reduce the negative effects that come from breaching that threshold for a prolonged period.

A large patient survey led by CS Holzman and L Jason - 2019, revealed that many different stressors can cause or contribute to symptom exacerbation and worsening health. These should be taken into account when managing energy and activity levels to avoid or reduce PEM.

Stressors that can exacerbate patients' symptoms include -

- orthostatic stress
- pain
- sleep deprivation
- cognitive effort
- social interaction
- sensory stimulation: bright lights, noise
- busy environments
- emotional stress - grief, anxiety
- temperature stress
- hormonal fluctuations
- food and drug intolerances
- alcohol
- allergies
- environmental chemicals/ perfumes
- physical activity and exercise
- graded exercise therapy
- graded activity programmes
- 're-enabling' programmes
- therapies based on false premises ie deconditioning - could include CBT
- inadequate pacing – exceeding a tolerated energy envelope
- undiagnosed or badly managed comorbid conditions. ie. MCAS, IBS
- infections

For around 25% of patients, essential activities of daily living and accessing medical care can cause them to repeatedly exceed their energy envelope, contributing to long lasting post-exertional malaise and deterioration in health.

Depending on level of illness, aids such as wheelchairs, stairlifts, shower stools, resting places on stairs, grabrails, ear defenders, blackout blinds, home-helps, carers and support with accessing disability benefits, can help patients save energy - so they can try to manage their energy expenditure more effectively.

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