



# Building your Post-Exertional Malaise (PEM) Toolkit



Webinar hosted by: Laura Allen and Kate Herbert

## Slide 1 summary

Hi everyone, welcome to day six of ME/CFS awareness week at Emerge Australia. Today's session is about post-exertional malaise (PEM) and sharing ideas with each other to build our PEM toolkits. My name is Laura, I'm the Patient Support Nurse at Emerge Australia. I would like to introduce Kate, Kate is our clinical educator, she is a registered nurse, and her projects focus on teaching our clinicians about ME/CFS.

I would like to thank the Medical and Scientific Advisory Committee at Emerge Australia for reviewing these slides that I am sharing today.

## Acknowledgement of Country

*I acknowledge and pay my respects to the Traditional Owners of this land that I stand on today the Wurundjeri people of the Kulin Nation.*

*I pay my respects to their Elders, past, present and emerging.*

## Emerge Australia

National patient organisation supporting Australians living with ME/CFS.

- Education
- Advocacy
- Research
- Support Services



## Slide 4 summary

Emerge Australia is a national organisation, we provide support to 250,000 Australians impacted by ME/CFS. We have four focus areas, Education, Advocacy, Research and Support Services.

## Patients are our best teachers, learn from ME

- Learn about Post-Exertional Malaise (PEM)
- Share tips with each other, on how to care for ourselves during PEM



## Slide 6 summary

Most of what I have learnt about post exertional malaise comes from the community. So, today we're going to learn about post exertional malaise, and as a community we're going to share tips with each other because patients really are our best teachers.

# What is ME/CFS

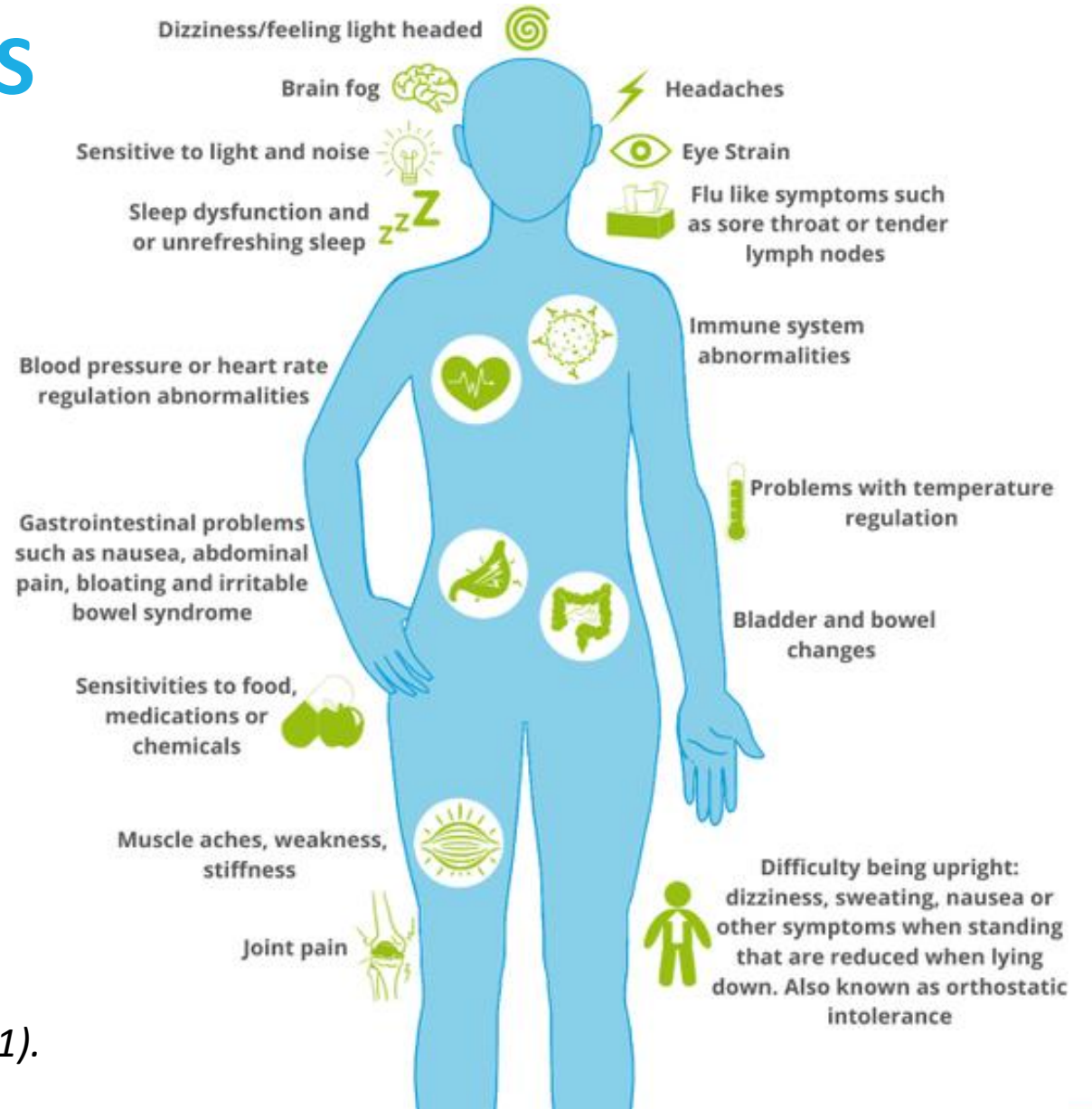
## Complex and disabling disease

- Brain
- Muscles
- Digestive
- Immune
- Cardiac systems

## Post-Exertional Malaise (PEM)



ME is classified as a neurological disease by the WHO (WHO, 2011).

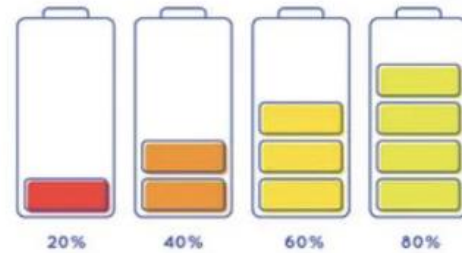




## Slide 8 summary

ME/CFS is classified as a neurological disorder by the World Health organisation. It's complex and disabling. It impacts many parts of the body including the brain, muscles, digestive, immune, and cardiac systems among others. During Telehealth Nurse consultations, we often refer to 21 common symptoms, but patients can have a list that goes far beyond this.

## Post-Exertional Malaise (PEM)



"Fatigue is what we experience – but it is what a match is to an atomic bomb"  
Laura Hillenbrand

## Slide 10 summary

I decided to talk about post exertional malaise because it's a core symptom of ME/CFS, and is wildly misunderstood, not just by clinicians but often by patients. It causes a fluctuation in our capacity to move our bodies and an increase in debilitating symptoms. It can last for days, weeks, months and may cause a potential worsening of our overall disease.

## Functional capacity, symptom severity and PEM



*PEM is like a wave,  
it builds in intensity and then settles*

## Slide 12 summary

Living within the energy limitations of ME/CFS can be complex. It's about finding the delicate balance between activity and rest.

When ME/CFS came into our lives, our body battery stopped charging to where it used to. When we use our bodies for simple activities (energy) the battery drains fast. The only way to charge our body is to balance rest and activity.

If we don't quite get that balance, we hit the "red zone" of the battery, and this is post-exertional malaise (PEM). During PEM we have a cascade of symptoms, and these symptoms build in severity and get worse.

## Slide 12 summary continued

One patient described this to me as, “it’s like a wave, the symptoms build intensity and then eventually they peak”. During this time, the only safe activity is rest. If we can rest (not everyone can) the symptoms will start to settle, the battery will start to fill back up and we will find the balance again.

Every person who lives with ME/CFS has their own level of activity that they can use, and their own amount of rest that they need. We are all different, but if we don't get that balance right, we crash.

Emerge Australia advocates for rest. Some patients report that consistent PEM crashes may lead to an overall worsening of their ME/ CFS disease.

# PEM

- Immediate
- Delayed
- Cumulative



## Slide 15 summary

Post-exertional malaise can have an immediate onset, a delayed onset, or it can be cumulative. Patients often associate immediate onset with using a large cognitive load, for example, being in a high sensory environment, tasks that require prolonged focus, reading, and processing information. Delayed onset can take up to 72 hours for symptoms to flare. Patients often comment;

- I don't know what it was that triggered PEM, was it that I went out on Friday to do the shopping?
- Was it Saturday when I didn't get enough rest and had a friend over in the afternoon?
- Was it Sunday when I finally dragged myself out of bed and into the shower?
- What was it that caused my PEM?



## Slide 15 summary continued

Next, we discussed cumulative PEM. I like to think about the onset of cumulative PEM as an accumulation of a slowly declining battery. Imagine we start with 40% battery, and during the day we use 20%. Overnight we go to sleep, but our sleep isn't restorative and we only add 10% to our battery. The following day we start with only 30% battery, if we continue this pattern, we will slowly hit that red zone and crash.

# Post-Exertional Malaise (PEM)



To watch the above video (with subtitles) please click the following link to the Emerge Australia's website (you will find the video half way down the page): <https://www.emerge.org.au/post-exertional-malaise-pem>

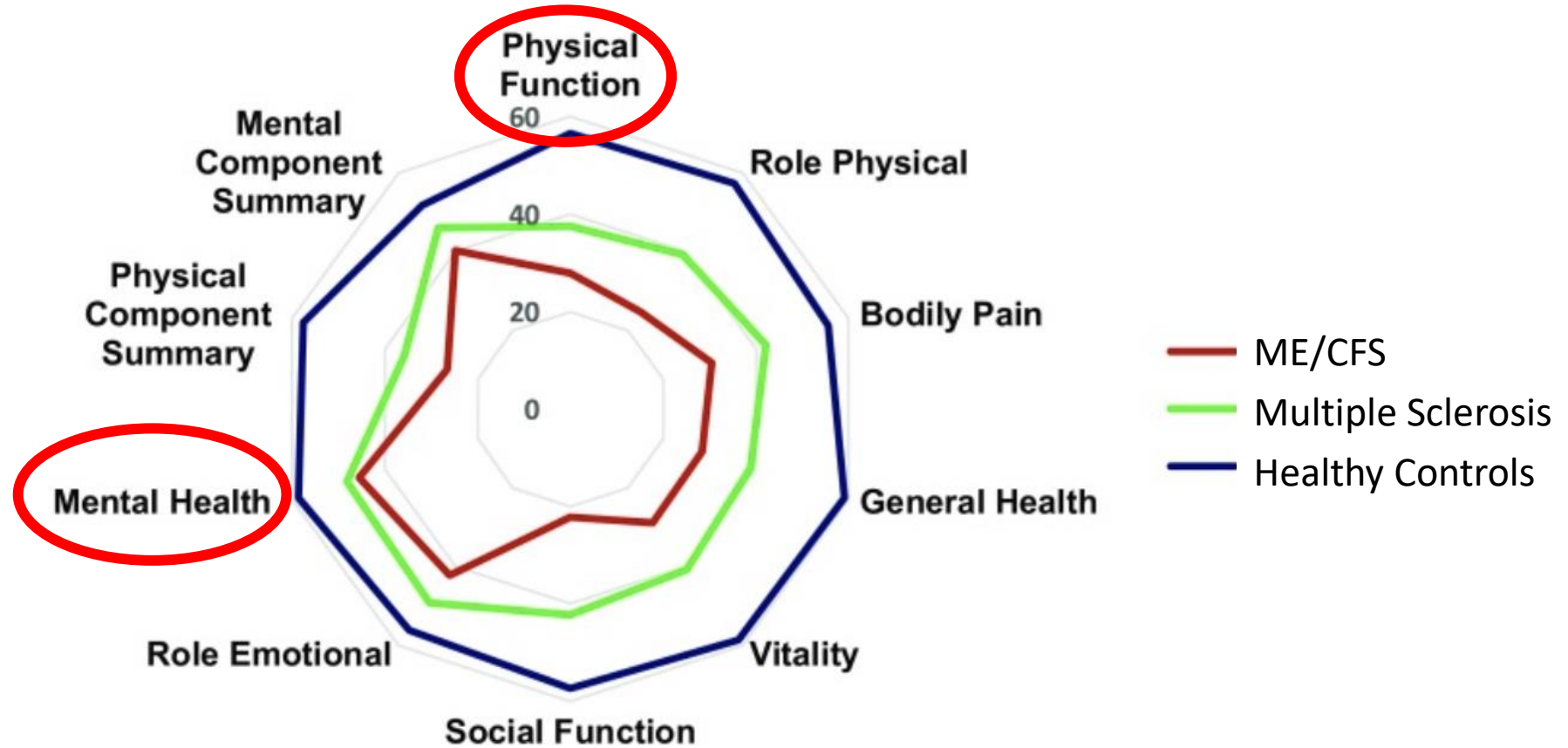
## The impact of ME/CFS and the science



## Slide 19 summary

Kate Herbert is the nurse educator at Emerge Australia and has a wealth of knowledge about ME/CFS. Today she's going to talk about the impact ME/CFS has on us and some of the research into post-exertional malaise and ME/CFS.

# The impact of ME/CFS is severely debilitating



(Kingdon et al, 2018)

## Slide 21 summary

The illness has a profound impact on the lives of those living with it. Many people with ME/CFS are unable to work or attend school or these activities are heavily impacted. I find this graphic helpful as it shows how much people with ME/CFS are impacted with everyday activities. The top circle is a series of questions that asks people if they can do really vigorous activities, all the way to can they bathe/dress themselves. You can see that the red line in the middle, people with ME/CFS have low scores. They aren't out running up and down stairs.

I think it also provides a helpful contrast with the mental health questions. you can see the scores are very similar to the MS group. It's common to have lower mental health scores as a group for any complex chronic illnesses but mental health problems are not the cause of ME/CFS.

# Exercise: CPET 24 hour test re-test

Decreased anaerobic threshold and peak oxygen consumption

	Test 1		Test 2	
	CFS	Controls	CFS	Controls
VO <sub>2 peak</sub> *	26.23(4.92)	28.43(7.27)	20.47(1.80)	28.90(8.06)
AT*	15.01(4.90)	17.55(4.85)	11.01(3.43)	18.00(5.25)
HER (%)	94.83(8.86)	87.0(25.44)	87.83(9.36)	97.67(7.20)
DUR (min)	9.3(2.44)	7.78(1.98)	8.35(2.51)	8.30(1.57)

\* ml/kg/min

VanNess, J. M., Snell, C. R., & Stevens, S. R. (2007). Diminished cardiopulmonary capacity during post-exertional malaise. *Journal of Chronic Fatigue Syndrome*, 14(2), 77-85.

## Slide 24 summary

Some of the clearest examples of what happens with physical exertion come from two day CPET studies. Usually, people get consistent results across both days, including people who are unfit, deconditioned and across a range of illnesses. For some reason, on the second day people with ME/FS show a marked decrease in measurements including how much oxygen the body can use

This was one of the first papers published by the Workwell Foundation who pioneered this test in ME/CFS. These results have been replicated many times and are considered robust.



## Slide 24 summary continued

The test consists of an individual exercising on a stationary bike, which is set to increased difficulty, until they reach exhaustion, and then repeating the test 24 hours later.

Based on the results of the first test, it does look like people with ME/CFS are just unfit. But the results of the second test 24 hours later show that this isn't deconditioning.

## Slide 24 summary continued

Very generally what these results are telling us are that people with ME/CFS have an impaired aerobic energy system – the aerobic energy system is the primary system used at rest and for ongoing activities - we generally think of it in terms of going to a gym session or a jog, but every day activities are aerobic including getting breakfast, dressing, showering, walking etc .

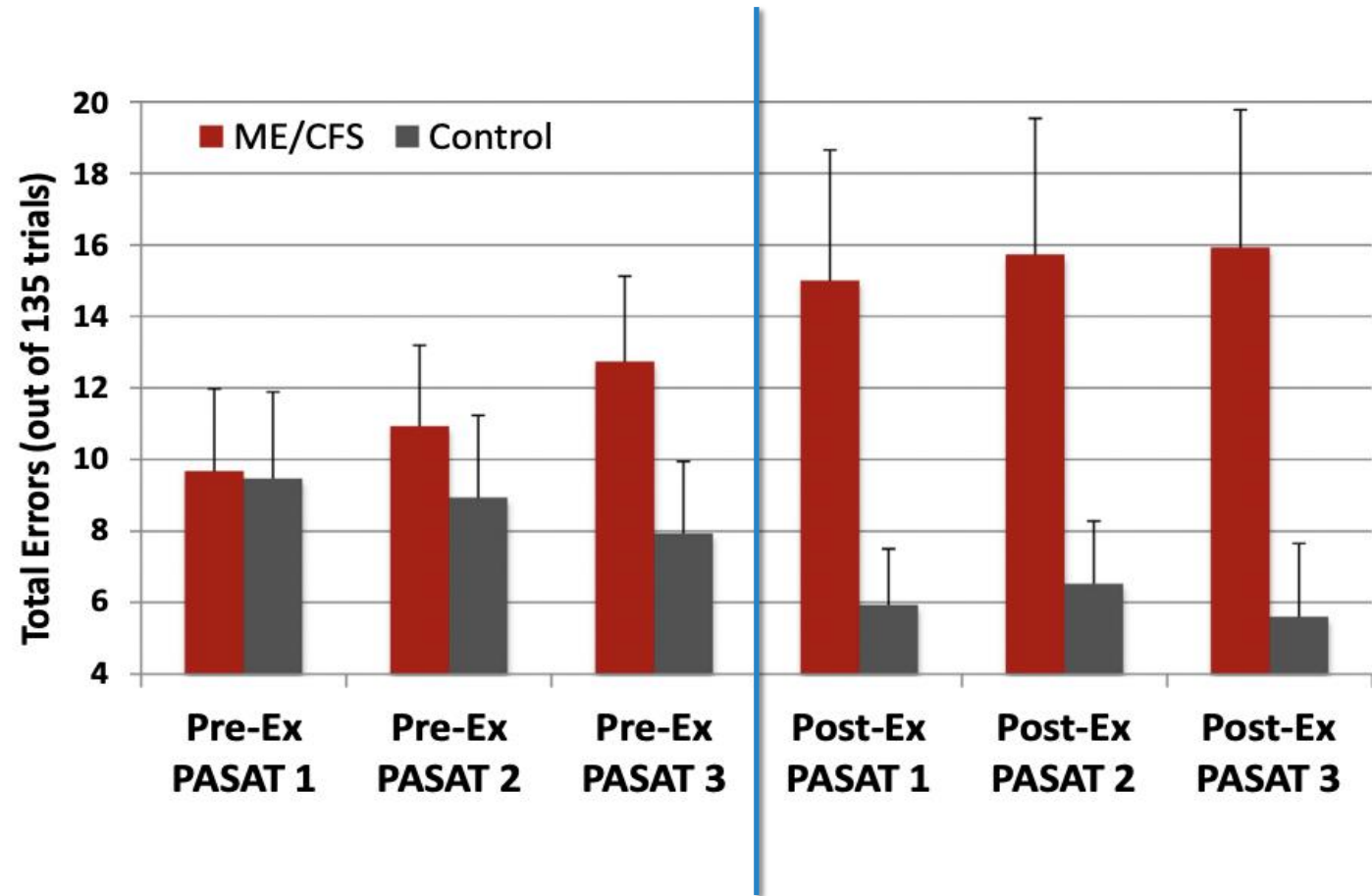
## Slide 24 summary continued

The Anaerobic threshold is when you cross from using aerobic energy as your primary source of fuel to anaerobic energy – anaerobic energy is for short intense bursts of activity. It's not for prolonged activity. The implication of this test is that there appears to be something wrong with the aerobic energy system in ME/CFS – so the system we use for everyday activities, walking/standing/sitting isn't working properly which helps to explain why normal activities have become really hard or impossible.

Importantly, aerobic training doesn't seem to help this issue but makes it worse. This test is considered a gold standard for measuring PEM in people with ME/CFS, though it isn't used in diagnosis because the test itself is harmful, because it induces PEM.

## Exercise and Cognition

Decreased  
cognitive  
functioning

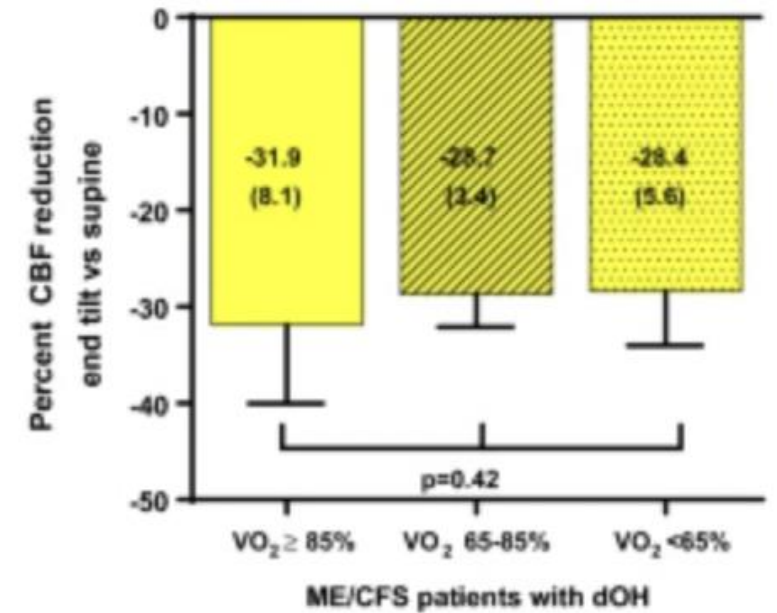
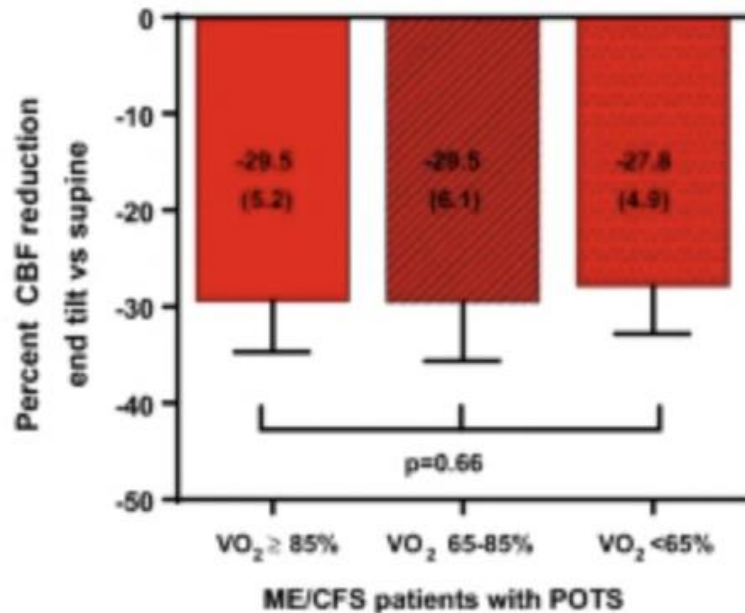
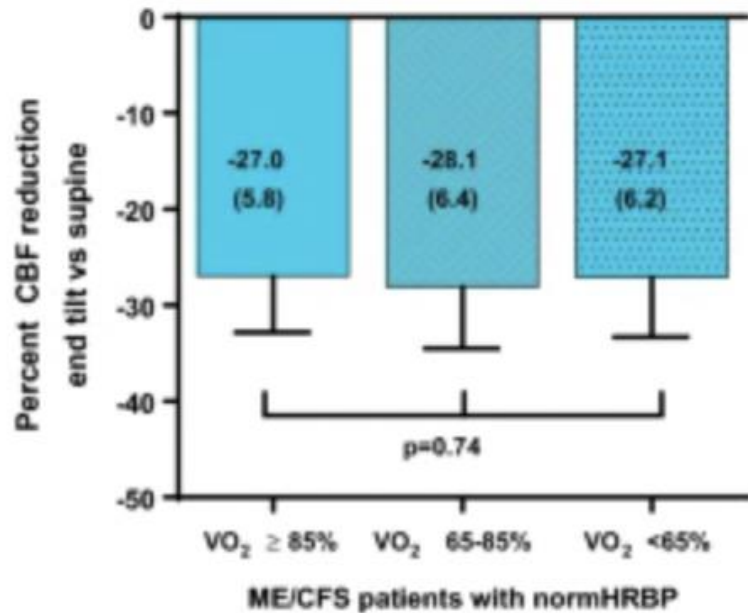


Cook DB, Light AR, Light KC, et al. Neural consequences of post-exertion malaise in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Brain Behav Immun.* 2017;62:87-99.

## Slide 28 summary

This image shows the total errors for ME/CFS and Controls doing cognitively fatiguing task before and after sub maximal exercise. They do the test three times before and after the exercise stressor. ME/CFS is red, and controls is grey. You can see for the participants with ME/CFS in the first three bars, even before they progressively had more trouble getting the answers right, and then after the exercise test it got even harder. You can see for the healthy controls with the grey bars, as they practiced, it got easier, and the results were even better after exercise.

## Reduced blood flow, not deconditioning



(VanCampen et al., 2021)

## Slide 30 summary

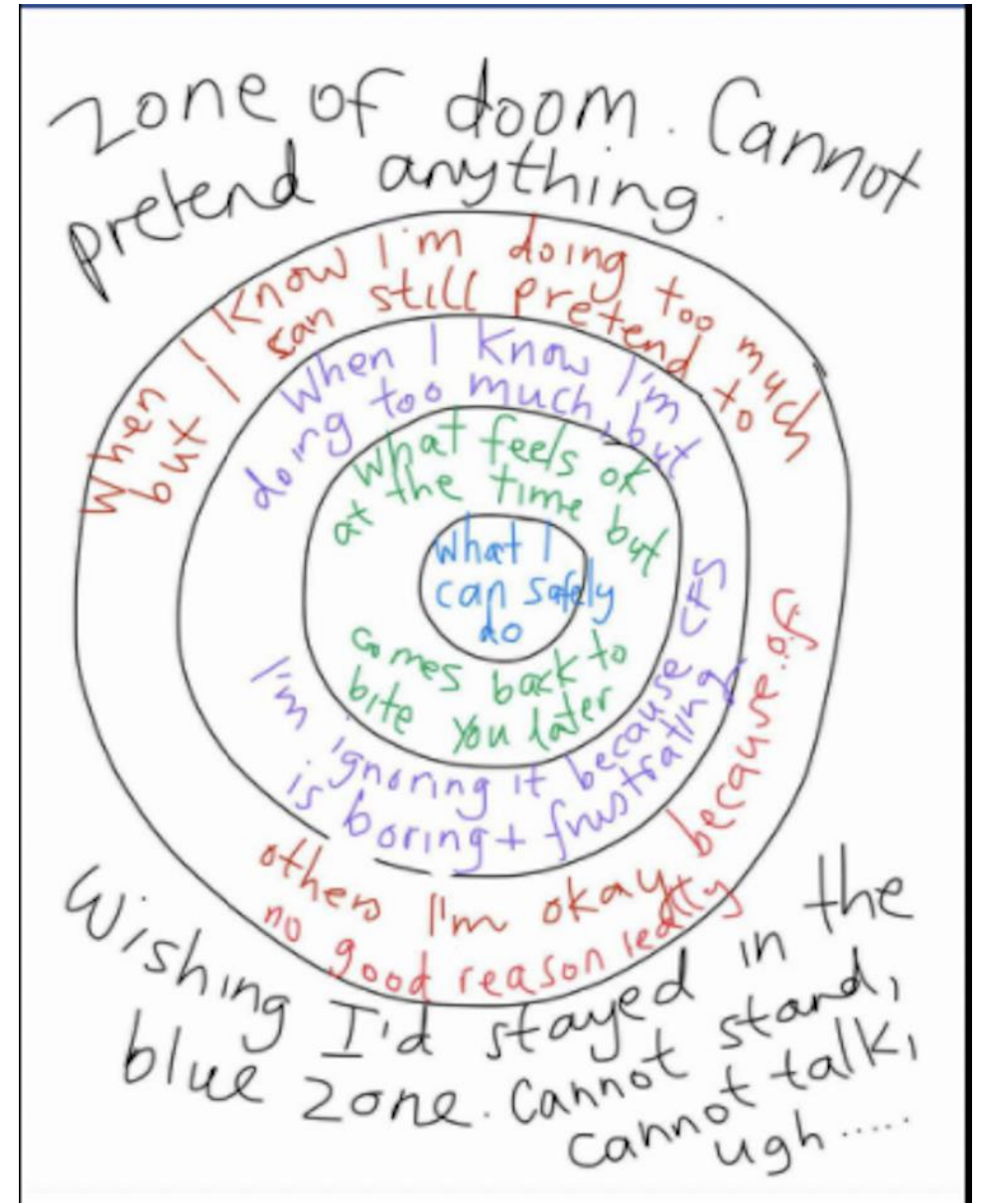
In this particular study they examined if there was an association between level of deconditioning and orthostatic intolerance. Orthostatic intolerance means your body is having trouble getting blood to all the places it needs to get blood to when you are sitting or standing. We know one cause of OI is deconditioning (there are lots of different causes of OI, not just ME/CFS), but in ME/CFS it looks like deconditioning is not the primary reason for the OI. This study found similar drops in blood flow to the brain across different levels of deconditioning and different types of OI. It's not entirely clear how OI contributes to PEM, but there is clearly reduced perfusion to the brain and other organs, and it's certainly something patients report as a problem. I'll hand back over to Laura now.

## Patient perspective

Continually triggering PEM  
can result in a permanent decline in function  
(Decary et al, 2021)

*“I feel like a battery that is never able to be recharged  
fully despite resting a lot and limiting my activities to only  
the bare essentials needed to get by”  
(NAM 2015)*

Used with permission from author: <http://slowtownsouvenirs.blogspot.com/>





## Slide 32 summary

This slide has been used with permission from the author. It gives an image of what it is to live within the energy limitations of ME/CFS.

**Blue Zone:** The centre represents what energy can be used to remain within the safe energy limits of ME/CFS.

**Green Zone:** This includes activities that we feel are ok, but there will be a little bit of payback, and we need to focus on resting and nurturing ourselves.

**Purple Zone:** This zone includes activities that trigger PEM, we need to be ready to rest and give ourselves self-care.

## Slide 32 summary (Cont.)

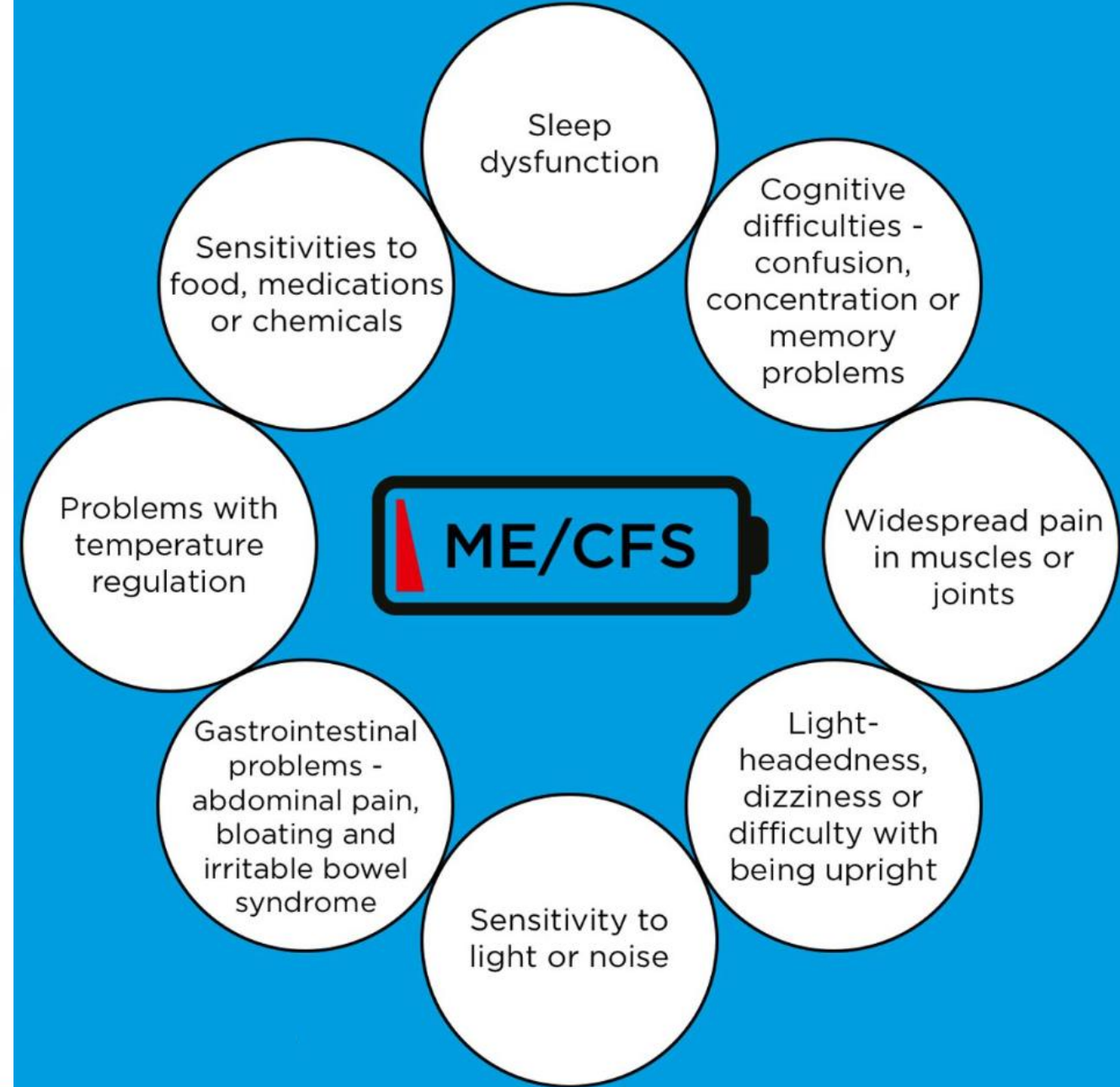
**Brown Zone:** We are in PEM and wish we could rest. Maybe we are out of the house, or we want to push through and enjoy that moment in time. We head towards the Zone of Doom.

**Zone of Doom:** “I can't pretend anymore” this author wrote, “I wish I'd stayed in the Blue Zone; I cannot stand it, I cannot talk.” I am in PEM; I cannot move.

Our responsibility is to rest, but that is not always possible. Some of us have children, are carers, or live on our own. We may need to cook, clean, and provide ourselves with nutrition. If we have the support through the NDIS (National Disability Insurance Scheme) or other means, we will stay close to the Blue Zone and occasionally touch the Green Zone and potentially move to Purple, but we would always pull back and make sure that we are able to rest, until we get back to that Blue Zone again.

## Symptoms that may flare during PEM

- Sore throat
- Tender Lymph nodes
- Tender skins
- Heavy limbs
- Headache



## Slide 35 summary

I'm not going to spend too much time talking about symptoms of post-exertional malaise, we know that there is 21 plus symptoms of ME/CFS. For this presentation, the focus is knowing our warning symptoms of PEM. Ask yourself “what is the first symptom I feel when I start moving into PEM?” Is it a sore throat, a headache, reduced capacity to concentrate, focus, a worsening of brain fog, sensitivity to the world, dizziness, or something else?

## Building a PEM toolbox

- Triggers of PEM
- Onset and frequency of PEM
- Duration of PEM
- Symptoms severity
- Functional capacity
- The most severe symptoms
- Management strategies
- Self-care, **nurture yourself**



## Slide 37 summary

This slide outlines how to build your PEM toolkit and this information will be uploaded to the website soon.

## Patients are our best teachers, learn from ME

*“I feel like a battery that is never able to be recharged fully despite resting a lot and limiting my activities to only the bare essentials needed to get by”  
(NAM 2015)*

[Information@emerge.org.au](mailto:Information@emerge.org.au)



## Slide 41 - 43 summary

The community share ideas to conclude the session and this will be uploaded soon



## Learn from ME

- What words do you use to describe PEM?



## Learn from ME

- How do you nurture yourself through PEM symptoms?



## Learn from ME

- If you could provide one piece of advice to a person who is newly diagnosed with ME/CFS, what would it be?





**Thank you for attending**

## References

Bateman, L., et al, (2021), Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management, in, *Mayo Clinic Proceedings*; <<https://doi.org/10.1016/j.mayocp.2021.07.004>>

Centers for Disease Control and Prevention, National Center for Emerging and Zoonotic Infectious Diseases (NCEZID), Division of High-Consequence Pathogens and Pathology (DHCPP); <<https://www.cdc.gov/me-cfs/index.html>>

Décary S, Gaboury I, Poirier S, Garcia C, Simpson S, Bull M, Brown D, Daigle F. (2021), Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *J Orthop Sports Phys Ther.* 2May;51(5):197-200. doi: 10.2519/jospt.2021.0106. PMID: 33930983

Friedberg, F., Sunnquist, M. & Nacul, L. (2021) Rethinking the Standard of Care for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *J GEN INTERN MED* **35**, 906–909;< <https://doi.org/10.1007/s11606-019-05375-y>>

National Academy of Medicine (2015), *Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness*, Washington, DC: The National Academic Press;< <https://doi.org/10.17226/19012>>

National Health and Medical Research Council, (2019) Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Advisory Committee Report to the Chief Executive Officer, <<https://www.nhmrc.gov.au/me-cfs>>

Kingdon, C. C., Bowman, E. W., Curran, H., Nacul, L. & Lacerda, E. M. (2018), 'Functional status and well-being in people with myalgic encephalomyelitis/chronic fatigue syndrome compared with people with multiple sclerosis and healthy controls', *PharmacoEconomics - Open*, no. 2, <<https://link.springer.com/content/pdf/10.1007%2Fs41669-018-0071-6.pdf>>.

World Health Organization. (2019). *International statistical classification of diseases and related health problems* (11th ed.). <https://icd.who.int/>

## Suggested reading

<https://www.emerge.org.au/>

Information on telehealth nurse, DSP and NDIS is under the "how to get help" tab

Carruthers, B. M., et al., (2012), 'Myalgic encephalomyelitis - adult and paediatric: international consensus primer for medical practitioners',

Bateman, L, et al., (2021) Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management in Mayo Clinic Proceedings <<https://doi.org/10.1016/j.mayocp.2021.07.004>>

<https://www.cdc.gov/me-cfs/healthcare-providers/toolkit.html>