

Heart Rate Monitoring

Why everyone with ME/CFS and Long COVID with Post Exertional Symptom Exacerbation should consider using it and how to do so!

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Core Idea of Heart Rate Monitoring

Heart rate can be an effective indicator of exertion, particularly over-exertion.

Backed by research and patient experience

Heart Rate monitoring enables you to set an alarm at a heart rate where you might start triggering post exertional symptom exacerbation if you don't modify your activity.

Staying within safe levels will help reduce Post Exertional Malaise and could lead to an improvement of symptoms and health. It is NOT a cure but an effective condition management tool

The data can also help you look back at your activities the last 7 days so you can see what is causing PEM and adapt your activities so you trigger less PEM in the future. HR readings across the day even when not triggering PEM can be indicative of energy used

Why you Should Consider Heart Rate Monitoring?

Post Exertional Malaise is unpleasant and more we do activities beyond our activity threshold the longer we can take to recover and the worse or symptoms can be

Less PEM often means a higher energy level for a day and harder to trigger PEM

We want to break out of the boom/bust cycle and have a good idea what the impact of activities is even if there is a delay

Having an external evaluation on how much energy we are spending on activities can enable us to try doing those activities in less fatiguing ways. We are not perfectly able to accurately assess activities on our own

It can help family and friends understand e.g. if you say “my HR is too high to do this activity, or I need to rest because at this level I am likely to trigger PEM” it is much clearer than just saying vaguely that you might have PEM issues if you carry on

The problems with other ways of identifying PEM

- We are not perfect at identifying PEM and PEM triggers ourselves
- We have biases
- Stimulants, adrenaline and much else besides can distort our receiving and noticing triggers
- What we might think are PEM triggers/tells could sometimes be something else e.g. dysautonomia issues, etc
- As PEM is often experienced much after an activity 12h to 6 days it can be hard to accurately attribute PEM to its cause

What Heart Rate Monitor to Use?

Factors to consider

- Type - Chest, wrist or arm
- Condition (new/second hand etc)
- Software issues
- Latest model or older model
- Are you wanting to be able to use HRV?
- Features beyond the HRM e.g. answering calls, monitoring sleep

Problems with current devices on the market

- Devices are not designed for this use
- Overly complex to set up
- Features you cannot turn off
- Harder to set alarms etc. than it should be
- Lots of features that just get in the way of core use

Minimum Requirements for Device

- Reasonable accuracy
- Reasonable comfort
- Sufficient battery life
- Alarm - needs to be on device unless you are happy to always have phone with you

Note whichever device you use you will need a way of charging the device usually by USB link e.g. a laptop or USB charger and also a smartphone or tablet with bluetooth capabilities

I Chose The Garmin Vivosmart 3- here is why

- Good price
- Sufficient accuracy and has key features needed
- Sufficiently comfortable for use

It is not the perfect device. The vibrate could be better, ideally you should not need to run a fitness session to get the alarm working and the battery life could be better. If you do pick this device (or the vivosmart 4 or 5) you will get more guidance from resources I have developed for running a project specifically using this device

How to Use a HRM for Condition Management

1) Set it up so you can wear it and start collecting data

If you don't wear your HRM device then you will not get any useful data. If you buy a reconditioned one then you can reset the data so you don't have any other data messing with your records

Find your Resting Heart Rate

Get used to the feel of the device

Start monitoring your activities

2) Set alarm to warn you if you are over a safe level, and follow protocol explained later if you go over

3) Review usage and modify alarm as needed

Activity Diaries - Use 1

Sample daily planner for mild/moderate M.E.

| Start time (approx.) | Physical activity (mostly on feet) | Mental activity (mostly sitting) | Rest and relaxation (sitting or lying) |
|----------------------|------------------------------------|----------------------------------|--|
| 8:00 AM | | | wake up, rest |
| 8:30 AM | Get up, have a wash | | |
| 8:45 AM | Make cup of tea | | |
| 8:50 AM | | Drink tea, watch TV | |
| 9:20 AM | Make breakfast | | |
| 9:30 AM | | Eat breakfast, TV | |
| 9:50 AM | | | Meditation practice |
| 10:10 AM | Wash up, tidy kitchen | | |
| 10:30 AM | | Make phone call | |
| 10:40 AM | | Check email | |
| 11:00 AM | | | Rest lying down |
| 11:30 AM | Weed the garden | | |
| 11:40 AM | | | Sit in the garden |
| 11:50 AM | Plant out new plants | | |
| 12:00 AM | | | Sit in the garden |
| 12:30 AM | Prepare lunch | | |
| 12:40 AM | | Eat lunch | |
| 1:00 PM | | Read | |



How to read your HR chart

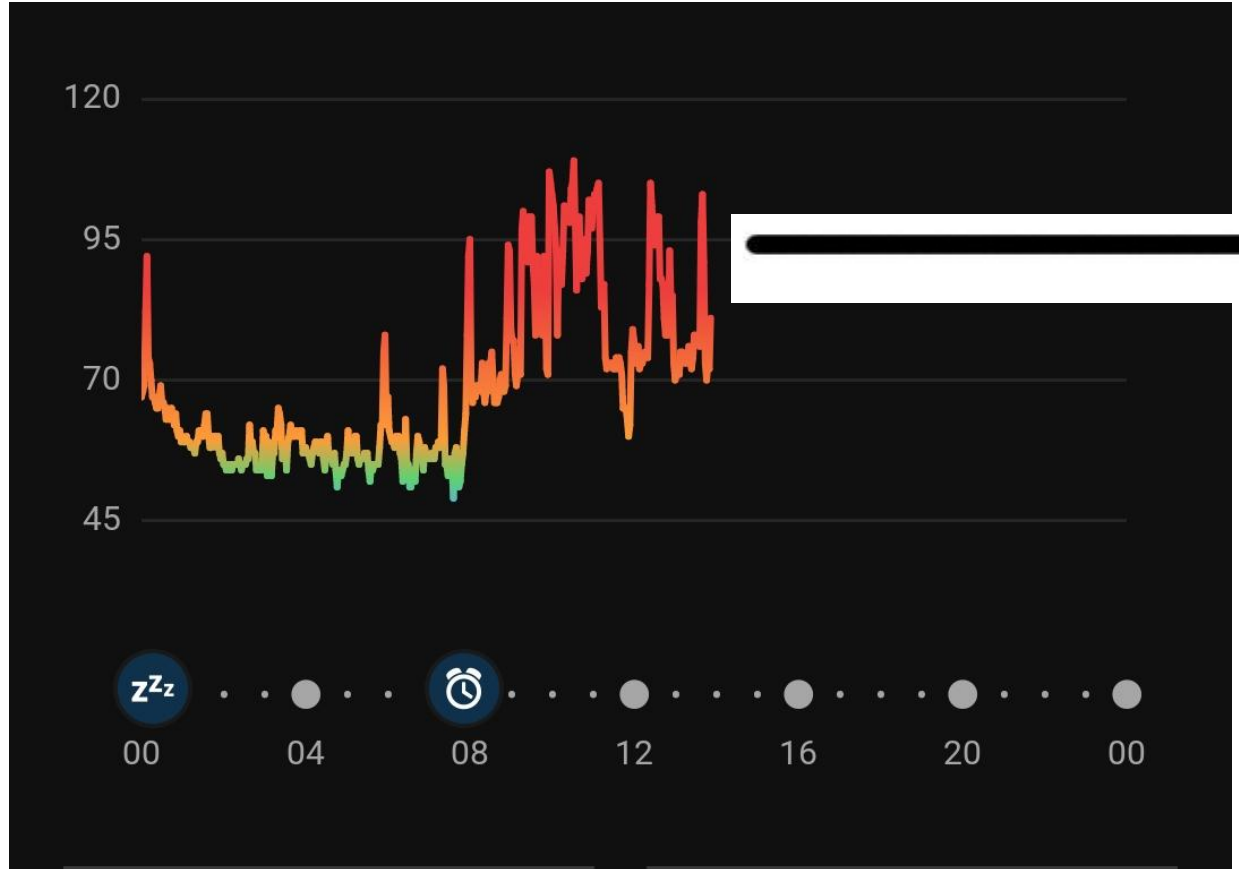
Look at peaks

Match with your activities

Where you are above
Threshold rate could you
have done anything

different?

What % of time in
different zones?



The Peaks

How to evaluate

How much are these over your threshold levels ?

Was there enough rest before and after?

Is there a way you could have broken up these activities more?

Could you have done these activities in a different way?

These all are trying to look back at what you have done and see how you could do it better in the future!

Note that these

What else to look for?

Are you getting adequate rest?

We all need different amounts of rest. I need about 20 min 3 times a day plus before and after tiring activities, plus more extended activities need to be broken down.

Be a fatigue detective - where you find you are experiencing PEM or fatigue symptoms look back at your activities and see what might have caused it. Could that activity have been done in a different way? Did it need to be done?

Mental vs Physical Activity

Heart Rate is only an indicator of whether or not you might be overexerting yourself or not. For some activities it can be more accurate than others.

Don't only rely on HRM. If you are feeling the beginnings of PEM try to stop and have a rest. Consider whether or not this is an appropriate activity for you or if there is a different way to do it!

For some cognitive tasks it might not show on monitor or it might show a lower rate. I recommend trying to stay within RHR + 15 for mental tasks.

What is the Heart Rate to set your alarm for?

It is very easy to get bogged down in the calculations but its “just” a guess

Two types of formula are used

- Resting heart Rate plus 15

- $208 - (\text{age} * .70) * 0.55$

Should you use the alarm all the time?

- If you don't set the alarm then you do not get the useful benefit of a warning
- You have to do what is right for you. It might be that you find it too annoying having the alarm go off when doing an activity like the school run that is really hard not to do then just having the device on without the alarm is sufficient for you.
- It is much better to take a day or morning off from using the device than to stop using it entirely.
- It might be for a typical day/activity its not needed as much
- Sometimes we can only deal with so many elements at once so if you need a few days not doing it, no real harm but neither are you getting the full benefits

What to do when the alarm goes off?

Can you pause the activity?

Pause and rest

Does the activity need to be finished? What is the lowest / safest way to finish the activity?

What can/should I do in the future

Is my alarm set at the right level?

Problem swatting

The alarm keeps going off? I have started ignoring it!

POTS or some other medical issue is causing my Heart Rate to shoot up on standing. Can I still use Heart Rate Monitoring

Remember the purpose of HRM is to help you. It is not to be another aspect of your life pushing you down

Take aways

- Cutting the grass takes me way over my threshold rate. I found that I can reduce this by taking breaks part way through, making sure the grass is never too long when I cut the grass or if so cut to a higher height. Now my daughter does most of the grass cutting
- Shower/bath - less hot shower/bath reduces HR increase and should reduce fatigue
- Walking the dog is often too fatiguing. When her behaviour is bad it gets much worse
- Walking my daughter to school can take me way over threshold

Do you need to wear a device all the time?

- If you don't wear it then you do not get the benefit of the data
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When will HRM not be useful or be problematic?

- Orthostatic Intolerance and/or heart rate abnormalities e.g. SVT
- Adolescents - Not been adequately tested on children and young people
- Issues with medications that regulate heart rates
- Need to be able to understand and follow the protocols - not enough support is really available out there
- Severe PEM issues

Resources

- Facebook group - <https://www.facebook.com/groups/MECFHS.HRM.2> and see <https://www.facebook.com/HRM4Pacing/>
- Workwell Foundation - Info sheet - <https://workwellfoundation.org/wp-content/uploads/2021/03/HRM-Factsheet.pdf>
- Videos including Professor Davenport's for Stockport ME Group on Youtube
- New book coming out from Physiosforme which will cover HRM as part as well as all aspects of ME/CFS management
- Resources produced by me for a research project on using Garmin Vivosmart 3 device
- Email me - benwickens55@gmail.com

