

How to Use a Heart Rate Monitor to Help With Condition Management

For ME/CFS and other conditions where Post Exertional Symptom Exacerbation is present.

By Ben Wickens

Note this guide may end up forming part of a book I am working on. If you have any comments, corrections or suggestions please feel free to email me at benwickens55@gmail.com

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Contents Page

- 1 The What
Introduction and Core Concept
- 2 The Who
Do You Have Post Exertional Symptom Exacerbation?
- 3 The Why
How Heart Rate Monitoring Can Help?
- 4 The How
What Heart Rate Monitoring Device to get and why?
What Alarm Rate to Set
How to Use an HRM Device
Reviewing Progress
- 5 Endnotes
Why I make the recommendations I do
Troubleshooting problems
 - How to Calculate Resting Heart Rate?
 - Adapting HRM when other HR issues like PoTS or on medicationOther Uses of Wearable Technology
What Else Can Help?
Useful Resources
- 6 Appendix - How to set up a Garmin Vivosmart 3

1 Introduction and Core Concept

This guide is for people who experience Post Exertional Malaise/ Symptom Exacerbation (PEM) and want to know either how Heart Rate Monitoring could assist them or want to know how to get started with using a Heart Rate Monitor.

Your heart rate can give a good indicator of how exerting a particular activity is. This is particularly true with an activity that exceeds your aerobic threshold and might trigger post exertional malaise/ symptom exacerbation (PEM). There are three main ways that HRM can be used and will be covered in this guide; **the alarm protocol, monitoring and tracking activity** across the day and **auditing/assessing** the energy spent on different activities and different approaches to these activities. For all of these ways you will need to wear a heart rate monitor for most if not all of the time. You do not need to wear one when you are sleeping but people often choose to do so in order to make sure that there are no untracked activities that happen before or after the device is taken off. Also some people use additional functions on their devices to track sleep.

Alarm Protocol

Heart Rate Monitors(HRM) can be helpful in managing your condition because they can give you a warning if you are carrying out an activity that might cause you to exceed your aerobic threshold and trigger PEM.

Research has shown that we can calculate or estimate a heart rate level at which we might be triggering PEM and we can reduce this happening by trying to keep our heart rate below that level.

An alarm can be set so it goes off when we exceed this heart rate level and then we can adjust our activities to minimise the harm caused by triggering post exertional malaise.

There is no reason why someone else like a parent, daughter, partner or friend could not do at least some of the steps to set up a device for you if you find it difficult or fatiguing to do yourself.

Ideally you will set an alarm on a device to warn you if you are going over a certain numeric threshold on your heart rate monitor. This will either be something like 15 beats per minute above your resting heart rate or a more complex formula based on your age. It can take a little bit of calibrating to find exactly the right heart rate number to set the alarm for you and your circumstances but this will be covered in more depth later.

Ideally HRM should be done in conjunction with Pacing and Rest. Some readers will already be experts in pacing and some people will not know what the term means. Heart Rate Monitors can complement pacing for experienced pacers and also take a more central role when someone is new to the condition and is still to learn or to be shown how to pace and how to effectively rest.

Not everyone who uses HRM uses an alarm all the time every day but at the very least using one for several weeks can make a huge difference in identifying what activities you might be having problems with. And whenever you do not use the alarm you are missing out on the potential benefit of being warned when you might be over-exerting yourself.

Tracking and Activity Monitoring

As well as using a heart rate monitor to try to avoid exceeding our aerobic threshold we can also use heart rate as a good indicator of the activity and rest level of what we are doing and use the data HRM's collect to adapt and adjust our activities so we can manage our condition better.

Tracking and looking at the data of your heart rate each day can give you useful information that can assist you in managing your condition. We are creatures of habit and often do a small rotation of activities each day. If you find one activity causing you problems then likely it will do so again and you can monitor your activities to make sure you are taking plenty of rests and over time you can look at changing the activities and the ways you do them so you are less likely to be triggering PEM.

Many people with pacing support will be asked to complete activity diaries. These can be exhausting to fill in and are often not done in the most accurate of ways. Using HRM data can go a long way to replace the need for activity diaries as they provide so much useful data but even if you are still filling in a diary then HRM can be a big help in remembering what you were doing at different times of the day and also getting a good idea how exerting different activities were.

Later on in this guide I will go through how you can use the data from your HRM to look at how well you are pacing and how you can go about assessing your data and bringing about positive changes to enable you to manage your condition better. Ideally you would be doing this in conjunction with a pacing expert who understands HRM but this is not always possible, or indeed likely.

Auditing and monitoring activities

The third way that we will talk about using HRM is to audit and monitor activities you are doing. You can use your heart rate to get an indication for how good quality your rest periods are. Assuming you are not just recovering from a fatiguing activity then during your rest periods you should be able to get quite close to your resting heart rate. If you do not manage this it is possible that you are doing too much during your supposed rest periods like thinking about what you are doing later in the day, sending emails etc.

Equally you might be doing work on the computer and be well within the level you have set the alarm but you can still see the extent to which your HR indicates that the activity is exerting you. You can do the same with other more obviously fatiguing tasks and this again will be covered in more depth later.

Overview

When we are learning to rest and pace better we are very dependent on our own perceptions on what is and is not causing our fatigue and PEM. We all have biases and there are lots of challenges in accurately guessing and knowing, particularly in the early stages of managing the condition. HRM gives a semi-independent and external evaluation of the

activities we do and energy we spend. It is not 100% reliable but neither are our own perceptions.

2 If you have Long Covid or another condition where there might be Post Exertional Symptom exacerbation how do you know?

In an ideal world you would just speak with your medical expert and they would tell you. Unfortunately this will often not be the case because they either do not always or often know or do not understand what post exertional malaise or symptom exacerbation is. Many medics are much more confident if there are a few blood tests that can be done to confirm a diagnosis but this is not the case with PEM. We are seeing all sorts of horrific examples of people with Long Covid being told to do mainstream exercise despite there being evidence of Post Exertional Malaise.

It can be difficult to know what the cause of symptoms you are experiencing is. Fatigue can be caused by mental stress, dysautonomia/orthostatic intolerance, lack of sleep, breathing problems and much else besides. Someone recovering from injury can also find activities fatiguing.

If you are not getting the right help from the medical community then you need to be your own health detective. You need to start off by realising that you might have biases and look out for them. So you are more likely to find reasons supporting what you want to do and problems or reasons not to do the tasks, projects and treatments you do not want to do.

If you do something and then afterwards experience symptoms then that is a good starting point. It might be that you experience some of the symptoms hours or even days afterwards. Does rest reduce the symptoms? If you get high quality rest (not reading or watching TV, mind not racing or thinking too hard about anything) then do the symptoms diminish? Is there something else that could be the cause of the symptoms e.g. I get symptoms whenever I sit or stand that are eased by me lying down. This is not the same as post-exertional malaise.

One tip is that you can try doing pacing, rest and even using a heart rate monitor to assist in condition management. If it does not help then there is a good chance that your issues are caused by something else. Whilst

deconditioning is a real danger the harm of causing post exertional malaise is much greater even if there is not as much external evidence available yet. Some studies suggest that as many as 75% of people with Long Covid might have Post Exertional Symptom Exacerbation and whilst my personal experiences might suggest slightly lower numbers if in doubt it might be worth working on the presumption that you have PEM unless proven otherwise if you also have Long Covid.

<https://longcovid.physio/post-exertional-symptom-exacerbation>

Exclusions and issues

As long as someone has PEM then I feel confident in recommending that they give Heart Rate Monitoring a try. I do want to highlight though that not everyone who tries using a heart rate monitor finds it successful.

Some people struggle to set up their device properly, particularly for the alarm protocol. Some people never get round or do not understand how to look at the data that the device gathers. Other people have failed to understand and to effectively follow the protocols so have not been able to make best use out of their heart rate monitor. It is hoped that this guide will minimise the number of people who accidentally fail to follow the protocols and so can make best use of the technology. If you struggle with technology and do not have someone who can help you then it may be that this isn't the right tool for you at present but might be worth returning to when your symptoms are better managed.

People in a crash or who have severe ME/CFS can have problems using the alarm protocol. They may find that everything that they do could cause the alarm to go off. This can be more frustrating than helpful and will depend a lot on the person using it. The tracking data could still be very useful in trying to make sure they are getting as high a quality of rest as possible and in trying to make sure they do activities in at least an exhausting way. This is something that they will need to decide on a case by case basis. If someone is helping them with pacing then giving that person access to their data could really help with condition management and would be much less tiring than filling out a regular activity diary.

There are people who face extra challenges in using the data. These are covered later on but anyone who experiences PoTS type issues where their Heart Rate goes up by 30+ BPM on standing could have more challenges in effectively using a heart rate monitor for pacing. Similarly someone who has SVT where their HR can spike at any time of the day to high levels for short periods even in rest would face extra challenges in reviewing the data and also using an alarm protocol.

3 Why Heart Rate Monitors can Help with Condition Management?

Post exertional symptoms are horrible. I can get headaches, brain fog, memory problems, my motor skills can deteriorate. It can be mild or extreme, lasting a few minutes or days. Using a heart rate monitor can help you trigger PEM less often and less severely and that can reduce how much and how often you experience PEM. Sometimes there can be a delay between an activity and experiencing PEM so you cannot always just listen to your body and avoid triggering Post Exertional Malaise. It is common for it to be 12-24 hours after an activity before the PEM is experienced. It can also be 2-6 days! Unless you are tracking your activities with some sort of diary it can be really hard to know what might have caused the PEM if you do not use a HRM device.

Break the Boom/Bust cycle

When people are first ill or if they are struggling to manage their condition they are often in a boom/ bust cycle. They might spend a day or a few days being active and then spend multiple days in bed recovering. Often when they are in their “boom” phase they are so pleased to be doing activities and feeling human again that they can fail to notice signs of fatigue. Even if they were doing their best to find them there are too many activities going on to know what is contributing to the exhaustion and other issues that they feel days afterwards to know what they could have done differently. With HRM you can see the data showing your activities and it is easier to see the cause, even if it is several hours or days later.

More broadly though if you do good pacing and rest or use a HRM for condition management then you will likely find that you have broken the boom / bust cycle of your illness. Using a Heart Rate Monitor can help you do this.

Reduce Chances of Relapse

Whenever you experience PEM there is a danger that you could trigger a relapse. Obviously the more you go over your threshold and the longer you do so the greater the chance of a relapse. Relapses are horrible, debilitating and sometimes can take weeks or months to

recover from which huge amounts of sacrifices and effort needed to recover.

HRM's are affordable and once set up are pretty easy to use. There are some annoying issues because there is no device and software designed and developed for health management on the market yet. Still with a very small investment of money and energy you are good to go. It might take 15 minutes to set up a device and there is a very small learning curve before you can start receiving benefits.

Compared with standard pacing, using HRM needs less awareness when you are carrying out tasks. You can just go about your day and when the alarm goes off then you can react. It is much simpler. There is less of an issue of bias creeping in so if you enjoy a task or it feels important to you then you might be less willing to stop doing it. But the Heart Rate is just the Heart rate and it does not have these biases.

Increase chances of recovery

Many people find that once they trigger post-exertional malaise less often and less severely that their baseline of energy that they have and activities that they can do in a day increases. I cannot promise to the extent that this will be true for you and this can vary a lot from person to person from this happening to a very small degree to another person making a near full recovery. I would also suggest that minimising PEM seems to be more likely to help recovery than just about anything else that you can do. So if you feel you have plateaued in your recovery and looking actively for something else to try then reducing PEM is a very good place to start!

Can be other uses for the data

Using a heart rate monitor and other health tracking data was helpful to me in realising that I also suffered from PoTS / Orthostatic Intolerance type issues. The data can be used for other purposes which is an added bonus.

Useful to share with a pacing partner or expert

I think it is best to learn pacing or to use HRMs with someone else

supporting you. Whilst we are the best people to know what we are experiencing and feeling we are also full of prejudices and biases that can cause problems. There is also the problem that when you are experiencing fatigue and brain fog as is common it can be quite easy to misread or misinterpret some information. When I was learning to pace I would have struggled massively if I had not had support.

When someone else looks at your data whether it is your activity diary or your HRM data then they might notice something that you didn't whether because your brain fog got in the way, it was something you were subconsciously trying not to see or just because of their knowledge and experience supporting many people with PEM.

In working on a Heart Rate Monitoring project I would see different patients' data and I could discuss with them what they were doing during that day. It was very easy to see elements where their condition management could be improved just by seeing their data.

Keeps yourself honest when doing Activity Diaries

It is easy to forget activities you have done or write up your activities in a favourable way. The HRM will show what you have been doing (to an extent) to both remind you what you have been doing and to keep you honest with yourself.

Useful to review what might have caused PEM

If you are feeling awful and are not sure why you can look at the activities on the HRM for the last few days and you might see bursts of activity that might be responsible. You can also look at your activities on a day and check if it looks like you have been giving yourself the right amount of breaks, mixing up physical and mental activities and such.

The problems and barriers of using HRM for Pacing

Broadly speaking I feel confident in recommending HRM for anyone who experiences PEM/PESE but there are a few important issues and barriers that people should be aware of.

No ideal device to use

Most importantly no device at time of writing has been designed for this purpose. You are going to use a device that is designed predominantly for athletes and aspiring athletes to assist with their training and the same is largely true with the separate software that is available to use in combination with wearable devices.

I have done some work with Harry Leeming at Visible and they are working on developing software for people with Long COVID, ME/CFS and other long term health conditions that can utilise wearable technology to assist with condition management. In our research project half of people were given a polar device using Visible software and half were given a Garmin Vivosmart 3 using Garmin's own proprietary software. Even with a clearly written guide and videos showing people how to set up the devices with Garmin there were still about half of the participants needing some extra 1-2-1 support setting up their devices. I think this was not a representative demographic but it does highlight how much harder it is to set up a device when it was really intended for a different purpose.

Barriers to properly set up a suitable device

The second biggest issue is that without an ideal device on the market it can be quite hard for someone experiencing severe brain fog and other Long COVID symptoms to understand how to use a device and set it up properly. Often the devices need to be "hacked" or adapted in some way to actually do the job we want them to do.

With the Garmin Vivosmart range that I am using for a research project in HRM the devices and software will only warn you with an alarm when you run an activity/exercise setting. So what you need to do is run a 24 hour (or longer) Yoga session to actually get the device to work properly.

When you do that you do miss out on some other features of the software so there is a small trade off.

When you are suffering with Long COVID or ME/CFS it can greatly impact your disposable income and it can look very intimidating when devices can be costing more money than you have in your bank account. I would stress though that very suitable and usable devices can be available refurbished for as little as £12 but I appreciate that it can require a lot of mental effort to search and find for a device with additional financial constraints.

Lack of professional support around how to use the devices

For many health conditions there is lots of advice out there on what to do and how to do it. If you need to use a peak flow metre then despite this being a much simpler device than a Heart Rate monitor you will be able to get an asthma nurse to train you up and support you in using the device. This is partly because Heart Rate Monitoring is quite a newly discovered tool and partly because there is so little research and professional resources put into this area.

Young People

The formulas that we use for HRM are based around adults. I see no reason why the basic approach would not work for someone who is younger but there has been less testing on that age range so the numbers ($RHR+15, (208-70\% \text{ age}) * 0.55.$) might not hold quite as true. For PoTS diagnosis in young people doctors are normally looking for a heart rate increase of 40 rather than the 30 that is used for adults so it is not unlikely that the formulas for guessing aerobic thresholds are less accurate with younger people. I do not see this as being too big a problem but when health decisions for young people are often made in part by carers or parents and they are maybe less able to advocate on their own behalf with doctors and medical experts it is really important that more research is done in this area so that they can be presented with the most accurate numbers to work with.

With any age the numbers for the thresholds should not be obsessed over or interpreted too rigidly. It is not like a speedometer where you

need to stay below 30 in a 30 zone or could get a ticket and be breaking the law. It is an indication that the activity you are doing might cause PEM and it sends a warning to you so you have a chance at that time to change what you are doing. Over time for anyone the numbers might need to be tweaked slightly to do what works best for them.

People with dysautonomia, heart issues or medication that could impact heart rate

Lots of people with Long COVID and also ME/CFS also have issues with sitting or standing that are relieved by lying down. Within this sub-group there are a lot of people whose heart rate goes up considerably when they initially stand up. That potentially can cause issues with using HRM devices. In some cases every time someone stands up their heart rate will go up by 30 BPM so that could cause the alarm to go off a lot of times. It could make it impossible for that person to stay within their threshold levels and could make using HRM rather frustrating and less helpful than otherwise.

There are other health issues that can cause your heart rate to do weird things. You might be lying down resting and then your heart rate suddenly goes high.

You might also be on medication that suppresses your HR so that it does not rise as much on exertion. In some cases this will mean you need to adapt the formula/number to set your alarm to. In some cases you will need to accept that it will sometimes just go off and you haven't done anything you can change. You might want to explore using a device or software where it will only trigger an alarm when you have been above a threshold level for 2-3 minutes as otherwise it would go too often for you to be able to use effectively.

One person with far more experience of HRM than I have is of the view that sometimes these dysautonomia issues may need to be sorted out first before the benefits of HRM can be achieved. In my case I have dysautonomia and after getting Long COVID it has been far more debilitating than my ME/CFS or my PEM but I have still been able to benefit significantly from HRM.

I still feel that the potential benefits are so high that with current levels of understanding almost everyone should consider trying to use HRM. I would say if you have some of these issues you need to be aware that both you might be less able to rely on an alarm to stop you doing an activity that might trigger PEM till you really see how it works for you and also you might have more times when you get alarms going off and spikes in your heart rate that there is nothing you can do about.

Some people might find that they need to not use an alarm and just instead use the Heart Rate Monitoring elements.

There are other heart issues people may have that will impact and cause issues with using a Heart Rate monitor. These can even be issues that are under control due to medication because the medication itself might stop the fluctuations and rises of Heart rate that would warn you of potential PEM.

Because POTS is so poorly screened for and tested and most people do not track or are aware how their HR changes during activities it is probably worth it for people with an HR device doing an active stand test and seeing if POTS is likely. Equally some people have started doing HRM and it has shown that their HR is going dangerously high too often and that has resulted in medical examinations and referrals.

Severe ME/CFS, Crashes and PEM

When people have really severe PEM or are in a bad crash then just about any activity will trigger their alarm to go off if they are using their alarm, even passing wind, a cough and much else besides. That is even if they are able to have the device set up and get it working.

I still believe that there is some value in that with the right person it can be helpful to know that they are potentially triggering PEM and to minimise activity and the extent of exertion. However in some of these cases it could be more helpful not to set an alarm and just to use a monitor to assess how extreme some activities are for them i.e. how much they exceed their aerobic threshold and also to track other aspects

of what they are doing. It is quite possible someone can spend 5 hours lying down in bed and not actually get any proper high quality rest due to worrying about things, reading, looking at their phone etc. Recovery can require high quality rest and HRM can help see how well that is happening.

Heart Rate adjusting Medication

There are quite a few medications that people can be on that can impact their heart rate. This can mean that they would have reduced benefit from using HRM such as the HR would not rise enough when they are over-exerting themselves. More likely there could be situations where the medication people are on might mean a small change in the level to set an alarm. I will write more about this in the troubleshooting section near the end of this guide.

Physical vs Mental, Emotional and Cognitive tasks

Heart rate is not a perfect indicator that something will trigger PEM. It is quite possible that sometimes your heart rate will go above the VAR and you will not experience PEM and equally you can sometimes experience PEM without triggering your alarm.

This does not invalidate using HRM but it does serve as a useful reminder to highlight that this is an imperfect tool. HRM does seem to be more sensitive with physical than with mental, cognitive or emotional tasks. I do think that ideally you want to use effective pacing and your own experience in conjunction with HRM to minimise the PEM that you experience. It is worth noting though that if most of the PEM you experience is as a result of non-physical tasks then you are less likely to experience as many benefits from heart rate monitoring with an alarm, particularly if you are using the more generous age based formula.

Some people might respond negatively to the data and warnings from HRM

There are some people for whom HRM will not be suitable because they will either spend so much time looking at and studying the data that it will cause more fatigue than it will alleviate. Some people will get so frustrated at the frequency that alarms go off that they either turn off their

device or even in extreme cases throw it across the room. There are also issues where people might be overly self critical when they exceed their aerobic threshold or get panicked when that happens. For everyone using HRM there does need to be some individual calibration and adapting it around other health conditions and the life that they lead. For some people however the requirements will be too much.

Equally there are a lot of people who will , without support, misinterpret the protocols with HRM . This could reduce the benefits that they could potentially receive.

The Science around Heart Rate Monitors

I am not a scientist although I like to feel I have a scientific way of seeing the world and problems. There has been quite a bit of work done exploring the use of Heart Rate Monitoring and I am currently involved in a research project with The Workwell Foundation and others. Rather than me parrot other people's science and possibly get it wrong I would instead refer people to a video Professor Todd Davenport did with me for my local ME/CFS Group. <https://www.youtube.com/watch?v=Z9d63ciUPVI&t=1782s> . This gives a decent overview of how you can use heart rate to potentially assist in identifying when you might be triggering PEM. I would say that with PEM there is an element of uniqueness in terms of how each person experiences PEM and there can sometimes be cases where adaptations need to be made to enable it to work optimally for you. The challenge is to make sure that the adaptations are actually helping you and not just there because of any biases or resistance you have.

This is equally true of all aspects of pacing. On the one hand most of the data is received by you and you alone and only you can fully interpret it in terms of effectively managing your condition. On the other hand we all need to acknowledge that we have biases and prejudices that can distort and change how we interpret that data. It is very easy in the context of HRM for instance to assume that a device is not working properly or that HRM does not work for you when instead the issue is either that you do not like what the device is telling you or that for a range of reasons you have not yet done the calibration to set the alarm to the right level for you.

4 How to use

You are going to need to buy or borrow a heart rate monitor device. Once you have a device you are going to need to link it to your smartphone or tablet. Once you have done this you are going to need to install software on your device and then you will need to set up a heart rate alert.

There are lots of different devices on the market and it can be confusing to choose what device is best for you. Some of the more popular device brands people choose to use for condition management include Garmin, Fitbit, Apple and Samsung.

The more accurate the device the better it will work and this is particularly important if you are wanting to be very strict sticking with a particular heart rate. You also need a more accurate device if you want to be tracking your Heart Rate Variability as well. Look at the later section on HRV to see why you might wish to do this.

You can use a wrist device, an arm device or a chest device (with strap). There are advantages to each different type. Wrist devices are often more comfortable, easier to glance at but do not offer the same accuracy as arm or chest readers. They are by far the most popular type of device used for this purpose though. With heart rate monitoring you want to be able to wear the device almost all the time and many people find arm devices a bit unsightly and sometimes uncomfortable and chest straps certainly too uncomfortable to wear for such a sustained period of time.

You also want to make sure the device you get can be easily set up to have an alarm. Ideally you want the alarm to be on the device rather than needing to have an alarm go off on the phone/tablet.

Software wise you can use specific software or often just the default software that has been designed for the device.

Different devices have different features and some people like the ability to play music, measure and track other data or be able to receive calls

might all be factors in what device you purchase. You may already have a smartwatch that would do the job fine.

Once you have set up a device and wear it then you are already a long way to getting the benefits from using a Heart Rate Monitor. It will track your data and you can use that to assist you with managing your fatigue and PEM.

The device will only produce useful data when you wear it and turn it on. Many people using HRM have a device 24 hours a day tracking both their sleep and all their waking time. That might not be what is right for you but it certainly is not to be used the way an athlete might use HRM, just having it on when they are doing a specific exercise programme. You need to be wearing it most or all of the time.

What number to set an alert for?

I recommend when you first use a device that you go for a couple of days without setting an alarm. There are a few reasons for this which I will cover at the end of this section.

Once you have gone a few days you can look at your data and see what would be a sensible level to set your alarm for.

There are two different formula that are used:-

Resting heart rate plus x (usually 15 Beats per minute)

(208- 70%of your age) multiplied by 0.55

You will sometimes see slightly different numbers used here.

I would stress that it is both important not to get too over-focussed on one particular number and that it is really hard not to.

There is a very accurate way of finding out what your aerobic threshold is on a given day. You can do exercise testing with the right equipment and the right professional support. There are only two problems with

doing this - the only place I know that does this is the Workwell Foundation in California and two if you experience fatigue and post exertional malaise doing this might actually do your health harm as you are likely to be triggering post exertional malaise doing it.

So we are left with using estimates and deciding how conservative you want to be. If you have an alarm going off every minute then it's like an oversensitive car alarm you (and everyone else) will stop going out to check on it and eventually your car will get stolen. Set it too low and you will be doing activities that are likely to trigger PEM without getting adequate warning.

The right level is up to you. It will depend on how much you avoid all instances that could cause PEM and how much you want to focus on the most severe causes.

The two formula types are likely to produce very different numbers with the $RHR + 15$ likely to be much more cautious.

Some people have argued that using the age related formula the multiplier should not always be 0.55 but should vary between 0.50 and 0.70 depending on the extent and severity of the illness. I am less sure about that but I do recommend that you go for a few days without using an alarm so that when you set it, you set it at a level that is most right for you.

If when you look at your data you find that you have having lots and lots of times when you are going over $RHR + 15$ BPM then you can think what would be more useful for yourself initially, to be warned of each of these occasions OR to focus on the instances where you went over by larger amounts. At the same time you should be aware that if you are regularly going over the alarm rate (particularly the age based one) then you are probably overdoing it and this is likely very bad for your health.

Over time you can review and change the alarm levels. You might find that your heart rate seems to be able to reach 0.55% of your max heart rate without seeming to trigger PEM... in which case it would make

sense to set it a tiny bit higher.

I have found that when I do physical activities the monitor does its best job of warning me of when I might be causing PEM but with emotional, cognitive and mental tasks it is not so consistently reliable so I still need to effectively pace. I have found that even in these cases my HR is above RHR+15 BPM so that I find that measurement very useful. If I was trying to spend a day doing mental tasks I would certainly consider setting my alarm to a lower threshold to minimise the chances of harming myself.

Finally I would note that for some people on medication that adjusts their heart rate that they may need to adjust the number that they set the alarm for. This is covered in the troubleshooting section.

How to set up a device

Each device is different. I have put together a guide for how to set up and use a Garmin Vivosmart 3. You can use a user manual, watch Youtube videos etc. for most devices out there in terms of general set up. In order to specifically use a device for Heart Rate Monitoring for ME/CFS and PEM then there can be a few different issues depending on what device you are using. The answer will often, but not always, be in the manual but you can also ask the community online what they have done.

There is an excellent Facebook group that you can join that you can find resources and search for a guide to set up pretty much any HRM/Smartwatch device for this purpose. I did find that there were a few devices such as the Xiaomi Bands that I could not find a good guide for but it is possible that some of these devices are not really accurate enough or perfect for this usage. I would emphasise that whatever your budget there will be a device that is useful for you. There may be issues such as an alarm is not as easy to hear or is only available on a mobile device etc. But pretty much any device can still provide you with some useful data that can assist you. If you are willing to use a refurbished device and are patient you can get a device for as little as £15 second

hand and do not need to spend more than about £20-30 to get a good device.

What to do when the alarm goes off

Workwell foundation in their 1 sheet primer recommends that you stop the activity straight away and only carry on once your heart rate is within 10 of your resting heart rate. In terms of minimising chances of getting PEM and the severity of that PEM that is excellent advice but it might not be always easy to do in practice.

Instead I recommend that you take this approach:-

Can you stop or pause the activity?

If you can stop the activity then do so. Consider in the future whether you need to do this activity or if there is a potentially less fatiguing way you could do it. If you cannot stop the activity then consider whether you can pause and rest and if so do so if not till your heart rate is within 10 of your resting heart rate at least as long as you easily can for.

Also consider whether you can adapt the activity you are doing or do it in a slower way.

When I first started walking out the house with ME/CFS I walked with a stick seat and would stop initially every 10 metres or so and rest for a few minutes before moving again. It made it possible when I really needed to go out of the house for some reason to do so in a way that did less harm for me.

If you cannot stop or pause your activity or do it in a different way then do not worry. Carry on with the activity as normal but take a note of it. At the end of the day/week or whenever you get a convenient moment, review the times when your alarm went off and see whether these activities could be avoided, done in a different way or done by someone else.

It is not always easy or possible. It might be that you need your partner to do more of the school runs. I found that I need to cut the grass on a higher setting if the grass is long and take regular breaks as otherwise my heart rate was really spiking. I found by adapting the activity (and sharing the task more with my daughter) that it was less of a problem for

me.

If you find that the alarm is going off too often to think about then you might want to consider in the short term setting the alarm a little higher. Every time you can avoid an activity triggering PEM can be very useful but it is more important to identify and avoid major offenders than being in a situation where you either ignore your alarm or stop using it. If you do adjust your alarm to a higher level try to both bear in mind that you are probably doing activities that could be triggering PEM that won't show on the alarm and look to review every week or so whether you should be lowering the alarm rate.

I do find when it comes to certain activities people can get a lot of resistance to changing them. Really look at the language and way you approach activities so that you are more flexible and less fixed.

For example when I take my daughter to school when my energy is a little low this will usually trigger the alarm on my heart rate monitor. That is not too surprising as I typically need to lie down and rest for an hour afterwards. It is easy to think "I need to take my daughter to school so there is nothing I can do about it!". In reality though there is a lot that can be done. Maybe not tomorrow, maybe not next week. But over time it is possible for someone else to take my daughter to school, maybe my wife can do it more, maybe if she cannot in the job she is currently in she could in a different job. Maybe another parent could take her, maybe we could drop her off at that other house en route to school so it is less fatiguing for me. I could look at all of those options and still decide that I want to take my daughter to school and that the consequences are worth it. What I am not doing though is viewing the situation as permanently fixed and without solution.

Equally someone might work 3 days a week and when they are working their alarm is just going off so often that it does not feel constructive for them. They could easily decide that HRM is not for them because it "does not work" with their current life. In reality it may be that they can just not set an alarm on those days and track activity. It may be that they could look at different, less PEM causing employment. They might be

able to look at different adaptations , reasonable adjustments or accommodations from their employer and they could find a safer way to work.

I was finding that my alarm was going off whenever I brushed my teeth. I need to brush my teeth but I was able to explore doing this task in a different way and see what was causing less of a heart rate spike. So now I brush my teeth for longer but less vigorously. I also generally sit down whilst brushing my teeth. Now brushing my teeth does not trigger my alarm and it seems to take me less energy to do it.

I find showering and bathing very exhausting as many of us with PEM do. Long before I used HRM I discovered that for myself if the water is nearer room/body temperature then it is much less fatiguing for me than if I have it hotter (as I like to do). I made this adjustment and it made a big difference. I also find it less fatiguing if I use my shower seat which I sometimes do (and probably should do more). Using my heart rate monitor it was interesting to see how easily I could look at the data of my heart rate and it confirmed something that took me literally years to discover without it. So regardless of whether an activity is actually triggering an alarm, heart rate monitoring can be used as a way of measuring the potential energy an activity is taking and we can experiment and see if we can find less energy using ways of doing the same task.

Using a Heart rate monitor as an indicator of energy spent is never going to be entirely accurate and at lower (pre alarm levels) it is probably even less accurate but I still feel that this can be a helpful tool for regularly carried out tasks to experiment with.

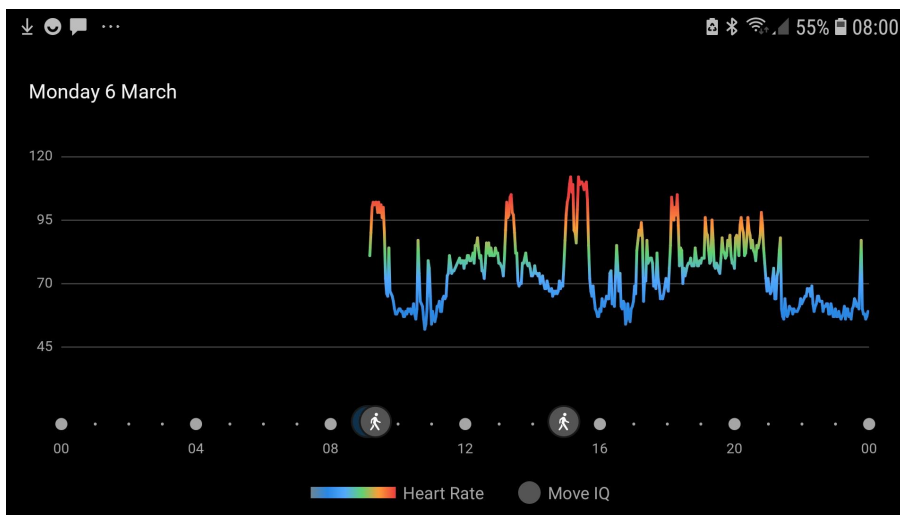
How to look at your daily data

Ideally you are going to do heart rate monitoring in conjunction with pacing and ideally if you are new to this you will have an expert helping you. I appreciate that this is not always possible but it can be really useful to have a second opinion as we all have lots of biases and it's also really useful to have other people's perspectives.

Here I will cover how to look at the data if you are not primarily doing pacing as well as otherwise you will be also using that data as part of activity diaries and everything else.

Look at the peaks

How often do they happen, how long do they happen for and how much over your aerobic threshold do they go?



Focus on the biggest/longest peaks if there are too many to focus on. In each case have a think about what activity you were doing? Was it physical or

mental? How long did it go on for? Did you rest before and after the activity? I find that if I do something that is too exerting for me then the sooner and better I can get some rest afterwards the less likely I am likely to experience PEM and the less severe that PEM often is. Also resting prior to activities I know can be tiring can really reduce the chances and severity of PEM.

On the day above for my aerobic threshold I did exceed it at one point clearly on this day. This was picking up my daughter from school. I had been expecting my wife to do it but I needed to do it at shorter notice than expected so had to walk quicker and had less rest prior to the

activity than ideal. Also on this date I had a little more nerves/stress than usual as I was running the first of a series of pacing sessions online that evening to a new audience. I was more unexpectedly run down than usual at the start of this day. As a result, I mainly rested for the morning rather than working on tasks and projects as I might have otherwise.

You can also use the data in a different way. Let's say you experience awful PEM/PESE then once you have rested and recovered sufficiently you can look back at your data and see if you can identify the most likely causes or triggers of that PEM. It is not to arrest the culprit or lay blame but rather look at how you can use that knowledge in the future to minimise the chances and extent of future PEM.

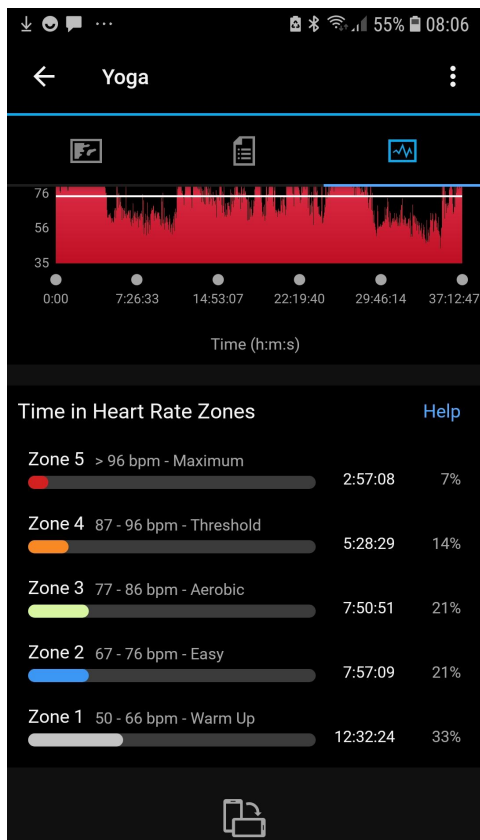
How are your rest periods?

I usually recommend that someone with PEM try to have 2-3 rest periods each day of 10-40 min in addition to any rests that they do both before and after activities. Often these rest periods can sort of act like putting your old mobile on to charge for a bit during the day...these periods can actually serve a restorative role and increase how much energy you have to spend across the day. The length of time can depend on how much activities you are trying to do that day (the more you do the more rest you need) and generally on how well you are. Some people take more time getting into the right restful state so a good 10 min of rest could easily take 20 minutes to get there.

With the HRM data you should be able to see these rest periods. Ideally HR should be close to resting heart rate. If you have just done a tiring activity you can actually find your heart rate can be higher during the rest than it was during the activity. As well as noticing and auditing the possible quality of the rest periods you can also see what percentages of the day were close to resting heart rate and what were if not over your aerobic threshold at least near it.

All this information you can use to see how well you are pacing and whether there is anything you could try to change to see if it helps you.

Reviewing your HRM progress



Over time you might find that you will want to adjust when you set your alarms for. It might be that you are finding that if you use the Age based formula there are times when you are triggering PEM and the alarm is not going off. You might find that say when you are doing some tasks that you cannot yet find a good way to avoid the alarm going off all the time is not helping you mentally or really in any way.

Remember that you can adjust the alarm number at any point both up and down and also that you can choose different times to have the alarm on or off depending on what best suits your needs.

It is important that you do regularly look at the data if you can so that you can learn from it. If you come to a conclusion that something is causing PEM then do actually look at what you can do so that this is not so damaging for you. It could be finding a way to do it less, have someone else do it, find a more paced way of doing the tasks or having aids and adaptations to assist you.

One person who was using an alarm found that it was never warning them of PEM. They were using the Age based formula and were doing very well with their health. They probably would have been fine if they just had used a lower alarm rate, such as that linked to RHR or just dropped the alarm by 10 BPM.

If you find that the alarm isn't picking up well with cognitive and mental tasks then just know that you need to use other tools in your pacing tool kit such as pre-emptive rests that much more.

Condition management is not just about avoiding activities that cause extreme problems but also that you are able to stay within your energy levels throughout the day. Ideally you want to be getting high quality rest and not be spending all the day “almost” triggering the alarm.

Exactly what levels you should have depends very much on your health and it can be different person to person and depends on what they need to be doing (or feel they need to be doing in a day). Your heart rate can be a fairly good indicator of how much time you spend in a day at lower levels of activity and how much rest you are getting. You can look at your data and try to ensure that you are having few (or no) periods where you are exceeding your aerobic threshold. Also you can look to try to ensure that when you are doing high HR activities where possible you rest before and afterwards (and during where possible).

Also you can check if you are getting enough time both getting high quality rest which will usually be very close to your resting heart rate level and also a lot of time at lower levels or “zones” of activity.

Ideally during rest periods you should be able to reach fairly close to your resting heart rate. This can be a good way of “auditing” rest periods. It can take a bit of time for your HR to settle at a lower level and if you were resting after doing something that over-exerted you then you might not find this to be the case but if it was a rest that you were taking pre-emptively, not because of over-doing it then getting close to resting HR can be a good way of testing how good your rest period was. It is not perfectly accurate but combined with considering how refreshed you feel and trying to objectively look at how “restful” your rest was it can be a very useful indicator.

HRM is a marathon not a sprint. It does not matter if you do it as well as possible all at once, just so long as you keep moving forward, making progress and continue to find it helpful.

Concluding thoughts

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 alone. 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 you might be triggering PEM without your alarm going off. I recommend trying to stay within RHR + 15 for mental tasks. I do not personally have my alarm set for this level but when I am doing long mental tasks I make a point to check my HR every 10 minutes or so as a precaution.

Remember that heart rate is only an indicator of PEM so I would not be overly concerned or trying to optimise what you do in terms of heart rate entirely. If you were, you might take a beta blocker or something that would lower your heart rate but not necessarily do anything that would stop you experiencing PEM.

5 Endnotes

Why I make some of the recommendations I do?

If you look at the information from the Workwell Foundation they recommend setting the alarm for 15 BPM over your resting heart rate. I think when you are doing HRM with expert support that is a very sensible thing to do.

It is my belief though that when you are trying to do this on your own it is important to minimise the chances of HRM failing for you. So if you try it and get annoyed by how often the alarm goes off or feel overwhelmed by the frequency of triggers it is very easy to take the device off, never wear it again and feel that HRM does not work for you.

So my focus on my recommendations is geared to minimise the chances of failure rather than getting the most benefits from HRM as soon as possible.

So my recommendations differ from the standard recommendations in a few ways:-

1) Wear a device for a few days without using an alarm - to get used to wearing a device and look at the data.

2) When you set the alarm, initially consider setting it slightly higher than optimal - Then set the alarm to a rate initially that will work for you. If you do set the alarm for something higher than the age based formula do review this on at least a weekly basis with an aim of bringing it down to this level.

Remember that the alarm is not your enemy or your boss. It is an aid to minimising PEM. It is much better to have a fire alarm that goes off sometimes when you are just cooking bacon with a little crispiness rather than when it doesn't go off and your house burns down. You are not a failure if the alarm goes off, even if it goes off much more often than you would like. Don't get lost in the weeds trying to avoid every little time the

alarm goes off and instead focus on “easy wins” and avoiding the most extreme potential causes of PEM. You can view every other time the alarm goes off as a potential future improvement of your fatigue and other symptoms as you are able to address those triggers in future.

There are some internet groups and patient advocates that argue for a much stricter application of staying within your aerobic threshold. So some will say ALWAYS stay within 15 BPM of your Resting Heart Rate. Others will not use this hard to manage rate but will still focus on staying within whatever number you set.

In terms of condition management I really feel it is important to look at the overall amount of energy you are spending each day and not get overly lost in the weeds focussing entirely on the peaks. I know with myself that if I generally pace well during the day, get some good high quality rest periods then the consequences of a minor amount of over-exertion do not seem to do any long term damage and are quite manageable.

If you look at diet we all know we should “eat 5 portions of veg a day”, not have too much sugar, salt, fat etc. but just because we might not have a perfect diet it does not mean we should be just giving up and not trying to eat healthier. HRM and pacing is a bit like that. It is better to be realistic with your own life and do what you can than try to do more than you can sustain and then give up entirely.

I would argue though that once you have stabilised to the best of your ability it can be worth reviewing what could be causing PEM, considering trying to stay stricter within aerobic thresholds. In some cases people have found that through stricter pacing they have found that they have made breakthroughs and experienced a significant improvement in their health as a result. This is not always quick, it can take weeks, months of dedicated focus and sacrifice but the payoff is huge.

Troubleshooting

Resting Heart Rate

I do not use my resting heart rate very much. This is because when I started using HRM I started using an age based formula as it was more manageable as a starting point. When I got Long COVID I found that my heart rate started going up by quite a large amount on sitting or standing that would have made it really difficult to keep within the RHR plus 15 or even 20 type levels.

I have found RHR plus 15/20 really useful as a guide of when mental, cognitive and emotional activities/energy I am spending might be causing fatigue but I do not use an alarm in calculating this.

As such I have not had to really look too much for myself at how RHR is calculated but I do want to make people aware of a few issues.

RHR is often calculated for people automatically on their devices. These calculations though are not necessarily “correct”. People have been critical of the way Polar and Garmin calculate RHR. So if you have these devices and use a RHR formula then this is something you might want to look at.

The Workwell Foundation suggests in their factsheet that if you take your HR on waking each morning for 7 days lying down and take an average of that for 7 days and that this will give you your RHR. Note that this can change over time so you might need to review it. Also it is possible that if you are in a period of crash that this time might not be an accurate reflection of your actual resting heart rate. If you are using this formula, as with anything you do need to adapt it to your situation and needs over time. You might find RHR plus 20 is sufficiently safe for you and more useful. You might not want to recalculate your RHR each week and just go by a number that is roughly right.

Adapting HRM to specific people

We are all wonderfully unique and our minds, brains and health issues can all mean we might need to use HRM a little differently.

I want to start with PoTS which is a really common condition. With PoTS people will have issues sitting and standing where they can experience a wide range of symptoms both immediately and delayed when they do so. They will also get in certain circumstances their heart rate rise by over 30 BPM on standing. In some cases their BPM will remain elevated and in some cases it will stabilise quickly. This can obviously cause issues in terms of using HRM to indicate exertion or even more so if they are using an HRM with an alarm.

If their heart rate stabilises on standing then they could look to use an alarm where it will only go off if their HR is above a level for over 2 minutes or whatever is right for them. This can mean that whilst they get slower warning of over-exertion there are fewer false alarms. It does depend very much on the individual. Some will be fine with the alarm going off and they understand that it is just because they are standing and there might not be much that can be done about it.

It is not known whether or not HR spikes such as this actually cause PEM or whether it is an exception. Some patient advocates think that PEM is still caused by exceeding their aerobic threshold. I, on the other hand, just do not think that this is proven. If you can have PoTS effectively managed and treated then obviously this is great to do so.

In my case I do not have PoTS but rather PoTS symptoms without Tachycardia Plus with orthostatic diastolic hypertension. My HR does go up quite a bit just on standing, much more than for someone else with ME/CFS but it is more in the 10-25 ish range. This would make using a RHR based formula for an alarm really difficult but I find I get a lot of benefits from just using the Age Based Rate instead and that is my solution.

About 50-60% of people with ME/CFS and Long COVID have some form of orthostatic intolerance issue although this is often not PoTS and does not always have a dramatic impact on their HR. It is so common though and so common that people do not know that they have these issues that probably people should carry out an "Active Stand Test" before starting to use HRM. HR will likely go up on standing (it is exertion after

all) but if it is going up by high rates, particularly if sitting/lying down exertion would not show similar increases then exploring a diagnosis of dysautonomia/orthostatic intolerance would be well worth looking into. In terms of HRM it may be that they need to set their alarms to a higher level or just track activities without setting an alarm.

Other people can find they get their HR spike at points for no obvious reason. It is fine to use a heart rate monitor if this happens. In fact it might be a useful precaution to track your HR data. However you obviously do not want to be judging yourself or making adjustments based on the alarm going off in these circumstances. If this happens during sleep then you might want to turn your alarm off during this period so it is not waking you and impacting on your sleep.

Medication can change your heart rate both in terms of what the general level (and Resting Heart Rate) is and also by how much it changes on doing activities. It is important to be aware that this can make HRM potentially less effective so you might need to be a little more cautious. It might be that taking one medication could increase your RHR by about 5 BPM. If that is all it is then if you use a RHR type formula then just make sure you adjust it for your new RHR and see how that works. It might mean small adjustments in what alarm level you set. It might in some cases make HRM just not really that meaningful. This really has the potential to get beyond what research is out there and the scope of this guide. I would encourage people in this situation who are keen to use HRM to reach out to some specialist groups and practitioners for assistance in this case. Otherwise just be mindful that you might need to make some adjustments for HRM to work effectively and safely for you.

Young people were not as involved in research on HRM as would be ideal and it is possible that the formula we use might work less well for them. This in no way invalidates using HRM with a young person or child but I would caution practitioner or parent led HRM where it is restricting what a child does or if it encourages them to do more than they feel they can safely do. It can be difficult for children to fully advocate for themselves and there have been lots of issues within the ME/CFS community of children being made to do too much by health

professionals and them not being listened to when they do too much. So I would encourage children and young people to start off for a little longer without using an alarm and then when an alarm is set it is set with their informed consent at a level they agree with where possible. There may be more need to review and change the alarm over time to ensure it is set at the best level for them to minimise PEM and also minimise the alarm going off when it would not be helpful for them.

Other uses and benefits of wearable technology

Heart Rate Variability - I could write a whole chapter on how HRV can be used to help with condition management. Instead I will highlight here that HRV is also a very powerful tool for you to consider using. Heart Rate Variability is much more complex to track than heart rate. It is looking at the variation in your heart rate rather than the heart rate in and of itself. In order to most fully utilise this data you generally seem to need a much more accurate device than you do for heart rate monitoring. This will often be an arm or chest reader and you will need potentially a higher spec device to be able to get useful data.

If you record your HRV for a set time each morning you can then get data on the changes in your HRV that some people find very useful. Many people who experience PEM/PESE report that they feel very different one day to the next and that they do not always know what they will be able or not able to do on a given day.

HRV can give you a good estimate of whether this is a low or high energy day for you as well as track the general improvement/worsening of issues. It can potentially act as a way of measuring with some objectiveness the level or severity of a PEM episode.

Some people have found tracking HRV to yield more benefits to them than HRM so it is well worth considering.

Some devices and software use a version of HRV in different ways such as Garmin's "body battery" score. I have some doubts about this as data is only as good as its accuracy and using my cheap HRM device on my

wrist I am unsure that the data will be accurate enough to be helpful but I know many people who have found their “body battery” score to be more useful than anything else in their condition management.

Changes in Resting Heart Rate

I have not personally paid too much attention to changes in my resting heart rate except where triggered by changes in my medication. When it goes higher then I allow my HR to be a bit higher before resting when doing mental/cognitive activities whilst lying down but otherwise I do not track it. In their information sheet Workwell Foundation suggests that if your RHR is 10 or more above or below your average RHR then this is indicative that you might have been overdoing it and therefore ideally you show lower your activity levels for the day and the time you spend doing any activities.

Steps

I have turned the steps tracker off on my device. I do not care how many steps I take. We come from a world where the assumption is the more the better when it comes to exercise but that is ignoring that people with ME/CFS and many with Long COVID have exertion intolerance. You can usefully track your steps as long as you do not try to do “above” a certain level. Instead you can look to try to minimise the steps you do. You may also find yourself exhausted on one day and then you look at the steps you did, maybe that day, maybe the day before, maybe 6 days before and you can start to see how and why you are feeling the way you do. So tracking steps can potentially be very helpful. You may find you are doing much more walking, even in the same house than you thought. You can also track on some devices how much climbing you do and that can also be relevant data.

Upright Hours

Upright Hours is a term that has become better known if not originating from the Bateman Horne Centre. It describes how much time someone is sitting or standing. It can be indicative of someone with ME/CFS or Long COVID with PEM at one set of levels (4-8 hours upright) and fewer upright hours can be highly indicative of orthostatic intolerance. This is

trackable information and devices were specifically adapted for this purpose for some research. I am not aware of a device which currently tracks this is available at the moment but it could soon be.

Data for other conditions

You can use a smartwatch to gather data that could suggest issues with sleep, issues on standing (such as PoTS) or cardiology type issues.

What else can help?

Pacing

I have other resources available on pacing and there are a lot of excellent resources on it. You can get some benefits from HRM without even knowing what pacing is but much more is possible when you have all the pacing tools in your arsenal and in practice than when you just use HRM alone.

Rest

The single thing that helps me most is to make sure I get high quality rest each day. It is not popular advice and it can be really hard to do. Rest for someone with PEM is not the same as it was before they were ill. Watching TV, chatting with friends, mucking about on a smartphone...all these things might have been restful before but now they are likely to be significantly fatiguing activities.

I structure 3 periods of high quality rest each day of about 20 minutes. This is in addition to resting before, after and during potentially fatiguing activities. Learning how to get quality recuperative rest has massively increased my quality of life and what I can safely do each day.

Treat Symptoms

So often people who experience PEM are just told to get on with it and not given any support or referrals that they would get if they had almost any other condition. If you experience chronic pain then probably you need medication to effectively manage that and this should be reviewed regularly. In addition you probably need to be referred to a chronic pain

clinic for additional support. If you have sleep problems then maybe you need sleep medication or to be referred to a sleep clinic.

I started HRM before I got Long COVID and initially it made using HRM much, much harder as tiny amounts of physical activity would cause massive amounts of breathlessness, heart palpitations and problems. My HR would spike very easily. I started doing breathwork getting advice and support from the excellent Asthma and Lung UK Helpline and also resources from Physiotherapyforbpd website and the Stasis Life programme. After doing 2 weeks of breathwork I was able to do short walks again and a lot more physical activity whilst staying within my heart rate levels and getting much fewer problems that were in turn triggering PEM.

Explore Co-Morbidities and Rule out alternative diagnoses

For myself I have benefited a lot from identifying and removing foods and chemicals from my life as best I can that I was reacting to.

I discovered that I also had orthostatic intolerance and by restricting my sitting and standing I massively reduced the symptoms I was experiencing. Taking more water and a teaspoon of salt a day also made a big difference to me.

Doing breathwork massively helped with some of my Long Covid issues and actually enabled me to do more walking etc. without causing massive spikes in my heart rate. About 50% of people seem to have some sort of breath pattern disorder (also known as dysfunctional breathing) and treating this through breathwork or respiratory physio can mean you can have more energy and spend less energy doing some activities.

Useful Resources

Workwell foundation - useful sheet, videos online
<https://workwellfoundation.org/wp-content/uploads/2021/03/HRM-Factsheet.pdf>

Professor Davenport Talk - Stockport ME Group - gives an overview of using Heart Rate Monitors with a more scientific and theoretical perspective <https://www.youtube.com/watch?v=Z9d63ciUPVI&t=1780s>

Action for ME Pacing Guide
<https://www.actionforme.org.uk/uploads/pdfs/Pacing-for-people-with-me-booklet-Feb-2020.pdf>

Pacing support - many people find it difficult to learn to pace well on their own. A pacing friend or support makes a huge difference. It is so easy for us to just do the elements that we like to do

HR4M pacing Facebook Group

Activity Diary Templates

Final note

When I use “I” - I mean myself, Ben Rowe, someone who has had ME/CFS for over 10 years and Long Covid since January 2022.

When I use “we” I broadly mean the membership and committee of the Stockport ME group of which I have been co-chair for what feels like many years. I may also be meaning our membership and community in general.

This would not have been possible without Stockport ME Group giving me a platform to explore my ideas and projects around Heart Rate Monitors nor without the assistance of Professor Davenport, Dr Baker and others.

Apendice 1

How to set up a Garmin Vivosmart 3 for managing your condition through HRM

Note: - This device is now quite hard to get but 95% of this guide will also work for the 4 and 5 models and some will work for any Garmin device.

Introduction

Most devices will have a manual that you can look at should you wish. Alternatively this can be looked at online here

https://www8.garmin.com/manuals/webhelp/vivosmart3/EN-US/vivosmart_3_OM_EN-US.pdf . There are other videos or guides you can use to get the device setup and linked to your Smartphone/ Tablet.

You can watch the video I have made or you can read this guide - whatever works best for you. For initial set up you might find this youtube video helpful

<https://www.youtube.com/watch?v=LZIWzTDkdzk>

Once you have the device setup then you do need to set the alarm and the instructions for that are at on page 3 - or in the video linked here. Sometimes there can be minor differences to the process depending on your smartphone/tablet and on whether your device has been reset to factory settings. The Garmin Connect app is always being updated so it is possible that the screen options will look or be very slightly different than they are in this guide. You can have someone (a family member or friend) set up the device for you but you will need to know how to use the device once its set up. These details are at the end of the guide.

1. First Charge the Heart Rate Monitor - The device has USB charging so you will need a device to charge it with or an adapter (not included). I just charge mine with my laptop.

2. Restoring All Default Settings You can restore all of the device settings back to the factory default values. If the device does not show "hello" in different languages then I recommend that you do this. Otherwise skip this section.

NOTE: This deletes all user-entered information and activity history.



1. Hold the touchscreen to view the menu.

Select  >  > **Restore Defaults** >  ..

Now your device is ready to be paired with your smartphone/tablet but first you will need to install and set up the Garmin Connect software on your smartphone.

3. Installing Garmin Connect App on your Smartphone

Go into your app store and install the Garmin Connect app. Whilst it is installing it might be worth making sure that your bluetooth settings are turned on. You will need this to pair the Garmin device

with your phone. It sometimes  looks like this when it is on or this when it is off 

Dont worry too much though because if your bluetooth is turned off then your phone will ask for your permission to turn it on during the set up.

4. Create a Garmin Account

Open the Garmin Connect app. You will be asked to create an account if you do not already have one. You will need to set up permissions for the phone. You will want to make sure that you give the app relevant permissions. It will ask you for a range of data such as age, height, weight etc and usual sleep times. It might also ask you to set up step goals etc. Unfortunately these devices are geared at people trying to be more active rather than manage a fatigue condition and not all of these unhelpful elements can be easily turned off.

5. Link Device to Garmin Connect

a) On the device select your language option

Swipe down once and then select EN for English (or whichever language you prefer) using the arrows to scroll up and down through options. Then select "Pair Now" using the up and down arrows to flip through options.

b) Next open the Garmin Connect App

(it may) ..if it doesnt go to 3 horizontal lines on top left, click on garmin devices from the menu, then add device)

It will want to pair a device to the account. Often the device (Vivosmart 3) will not appear on the list. If it does then select it otherwise select "Browse all compatible devices", select "vivo", then "vivosmart 3" Then select "connect". Make sure the phone and watch are near each other when doing this. Note that sometimes this will work first time, sometimes it will take several attempts and occasionally you will need to return to try again later...pairing devices does not seem to work 100% every time.

A code should appear on your Vivosmart device and you will need to enter the code into your app as prompted.

You will then have a few set up options to go through including sleep times, orientation of display, preferred wrist to wear the device on etc. I recommend skipping the goals section. You will be given options to allow access to notifications, calendars etc., manage calls, receive text messages etc. it is your choice whether you want to use these features on the device or not.

Congratulations you have set up the device!

How to set Heart Rate Alarm

First find the beats per minute number to set for the Heart Rate Alarm

For this project we are using one of these two formulas. It is likely with most people that the second one will give a more restrictive heart rate maximum.

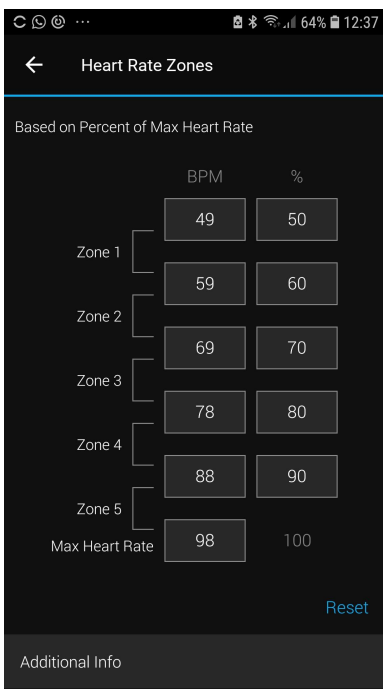
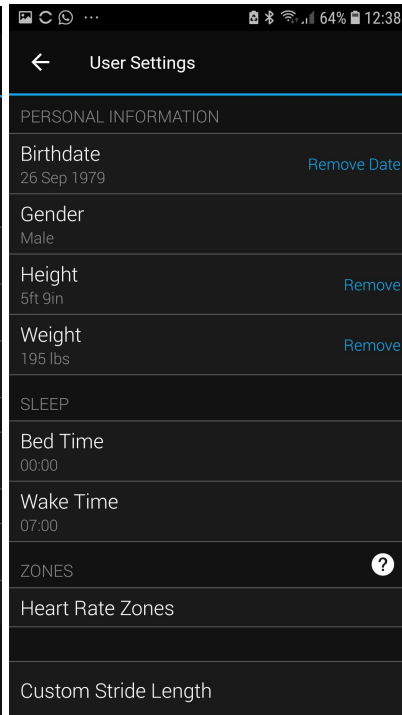
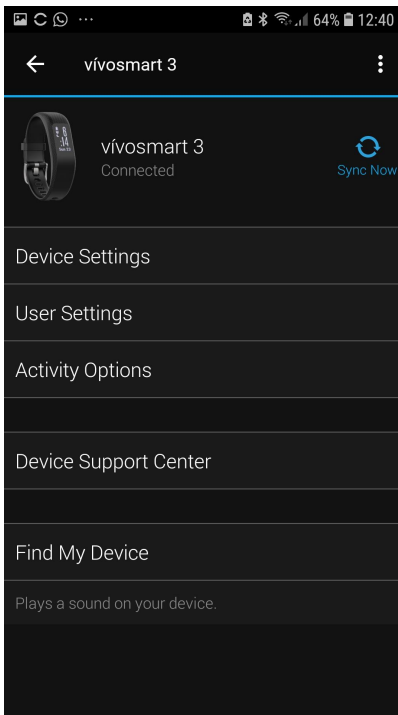
i) $(208 - 70\% \text{ of age}) \times 0.55$ (you can either calculate this directly or use the table below)

Or

ii) Resting HR plus 15 beats per minute. If you wear the watch for a day or two it will do a fairly accurate job of calculating your resting heart rate which you can then add 15 to or you do what the Workwell Foundation recommend in their fact sheet and do the following:-

“After waking, remain flat in bed and record resting heart rate with a heart rate monitor. Calculate the 7 day resting heart rate (by adding up results and dividing by 7).”

| Age | Heart Rate to set for alarm | Age | Heart Rate to set for alarm | Age | Heart Rate to set for alarm | Age | Heart Rate to set for alarm |
|-----|-----------------------------|-----|-----------------------------|-----|-----------------------------|-----|-----------------------------|
| 18 | 107 | 36 | 101 | 54 | 94 | 72 | 87 |
| 19 | 107 | 37 | 100 | 55 | 93 | 73 | 86 |
| 20 | 107 | 38 | 100 | 56 | 93 | 74 | 86 |
| 21 | 106 | 39 | 99 | 57 | 92 | 75 | 86 |
| 22 | 106 | 40 | 99 | 58 | 92 | 76 | 85 |
| 23 | 106 | 41 | 99 | 59 | 92 | 77 | 85 |
| 24 | 105 | 42 | 98 | 60 | 91 | 78 | 84 |
| 25 | 105 | 43 | 98 | 61 | 91 | 79 | 84 |
| 26 | 104 | 44 | 97 | 62 | 91 | 80 | 84 |
| 27 | 104 | 45 | 97 | 63 | 90 | 81 | 83 |
| 28 | 104 | 46 | 97 | 64 | 90 | 82 | 83 |
| 29 | 103 | 47 | 96 | 65 | 89 | 83 | 82 |
| 30 | 103 | 48 | 96 | 66 | 89 | 84 | 82 |
| 31 | 102 | 49 | 96 | 67 | 89 | 85 | 82 |
| 32 | 102 | 50 | 95 | 68 | 88 | 86 | 81 |
| 33 | 102 | 51 | 95 | 69 | 88 | 87 | 81 |
| 34 | 101 | 52 | 94 | 70 | 87 | 88 | 81 |
| 35 | 101 | 53 | 94 | 71 | 87 | 89 | 80 |



Garmin Connect Web Instructions

1. Sign in to Garmin Connect.
2. Select the icon for the Vivosmart 3 near the top right corner
3. Select Device Settings under the desired device.
4. Select User Settings.
5. Scroll down to Heart Rate Zones.
6. Change the Maximum Heart Rate to whatever is the correct value for you. You have the option of changing the other “zones” to whatever is helpful for you to visualise your daily

activity. I changed my zones so that zone 5 is my resting BP+15 but you do not need to edit them.

7. Select Save Settings.

2) Set up the activities - Go back to the "Device" menu - Select "Activity Options" - Use "Edit" (upper right) to choose which activities you want to display on your watch. Walk and Run can't be moved. -

For each activity: Select the activity, select "Alerts", turn on "Heart Rate Alert",

3) Sync your device manually, or wait for it to do it automatically (if you go back to the main page it



usually does it automatically).

4) On your watch, whenever you want it to alarm your high HR: - Press the "-" button(no button) -

Select the person standing on three dots - Pick the icon for the activity you want to use. (I use Other a lot, but any will work). - Wait until the alert has scrolled through and any options have been selected

(like GPS). - Double tap to start the activity. It will vibrate briefly and start the timer.

Finally to be able to use the alarm you are going to need to run an activity. We have already set up yoga.

(Select / Activate your device

Press the button

Choose other (scroll to it)

Double tap to start

-

To stop - save if you want to be able to look at the activity data, otherwise delete

Setting Your Heart Rate Alerts

You can set the device to alert you when your heart rate is above or below a target zone or a custom range. For example, you can set the device to alert you when your heart rate is above 180 beats per minute (bpm). You can use your Garmin Connect account to define custom zones (Activity Profile Settings on Garmin Connect,).

1 Hold the touchscreen to view the menu.



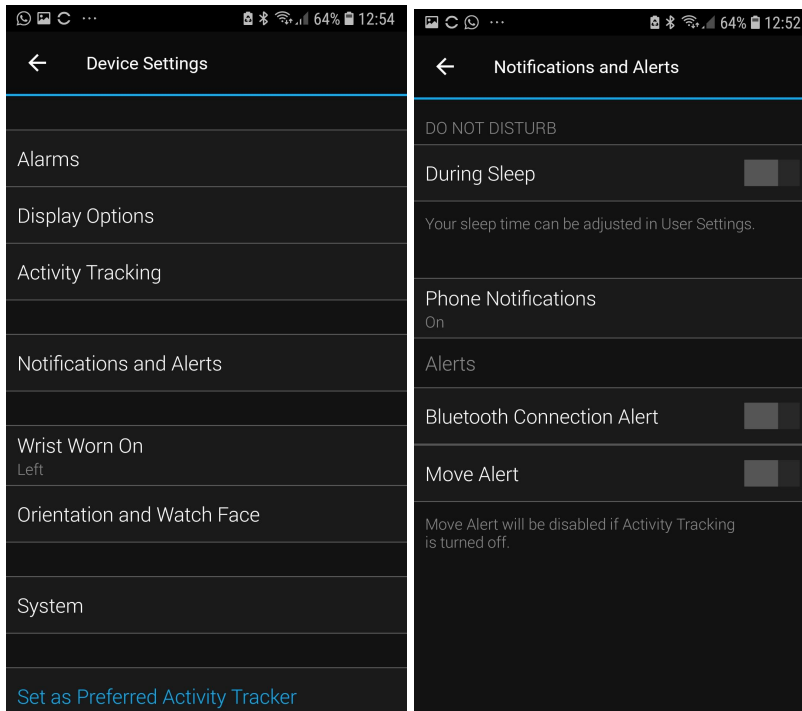
2 Select , and select an activity. I recommend using other. You might need to add xxx

3 Select Alerts > HR Alert.

4 Select an option: • To use the range of an existing heart rate zone, select a heart rate zone. • To use custom minimum or maximum values, select Custom. Each time you exceed or drop below the specified range or custom value, a message appears and the device vibrates.

How to use the watch ADD INSTRUCTIONS ON HOW TO DO BASIC TASKS

How to turn off Move alert



The move alert is an annoying feature that is not useful for people with PEM who need to rest during the day. To turn it off first go into Device settings on your Garmin Connect App. To do this open the app, then click on the picture of the Vivosmart in the top middle/right of the screen. Then

Turn off activity tracking

Turning off activity tracking (sleep, etc.) can extend your battery life. It will mean that you wont be collecting data that you might find useful so it is up to you. Alternatively you might find that the extra data is distracting.

To turn off activity tracking, open the Garmin App. Go into Vivosmart 3 device, select activity tracking and select the tab to turn it off.