

THE ART & SCIENCE OF PACING FOR ME

PACING : "TO AVOID DOING SOMETHING TOO QUICKLY OR DOING TOO MUCH AT ONE TIME,
SO THAT YOU HAVE ENOUGH ENERGY LEFT TO COMPLETE AN ACTIVITY"

- Macmillan dictionary

This dictionary definition is a good starting point for understanding Pacing for ME. In a nutshell, Pacing for ME means breaking up your day into (very) short periods of activity with (lots of) rest in between. It means prioritising important activities and dropping less important ones. It means finding energy-efficient ways of doing the things you have to - or want to - do. And it means stopping before you reach your energy limit and set off Post-Exertional Malaise (PEM).

THE MAIN GOAL OF PACING FOR ME IS TO REDUCE THE IMPACT OF POST-EXERTIONAL MALAISE (PEM).

▶ PEM is the reason why Pacing for ME is different from other types of Pacing used in other illnesses (see p.21). You can find detailed information sheets about PEM on our website (m.e.awareness.nz) and videos on dialogues-mecfs.co.uk. We recommend you check them out first but there is also a brief summary here on page 3.

▶ Short on time and energy? Read Emerge Australia's excellent 2-page introduction to Pacing (see p.27), then come back here and read the sections of most interest to you.

THIS INFORMATION SHEET IS FOR PEOPLE WITH ME* WHO EXPERIENCE PEM.

***If your diagnosis of CFS or ME was based on older diagnostic criteria
you may or may not experience PEM.**

This is an extensive guide to use as you wish.

INTRODUCTION

This article started life as a conversation between two people with ME, one with decades of experience of living with ME, the other recently diagnosed. The experienced person was helping the recently diagnosed one navigate through the jungle of contradictory advice found on the Internet. Notes were taken, drafts were made and debated vigorously within ME support groups, many changes and additions were made, and this is the result: an article containing many decades of combined lived experience with Pacing for ME.

This does not mean that all the advice in this article is right for you and your specific situation - we are all different. The advice given here is intended to give you ideas that might work for you. It's up to you to decide which ones are suitable for your own situation - and to seek professional advice if necessary. The information in this article is not a substitute for medical advice.

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PACING & PEM

To pace well you need to understand Post-Exertional Malaise, so here's a brief reminder of the key points of PEM:

- PEM is when your usual ME symptoms get a lot worse - and a few extra ones may creep in, too - after you've done more than your body can handle.
- PEM can be set off by any type of exertion. Physical and mental exertion are the most common triggers but other factors (temperature, noise, infections, etc.) can also contribute.
- PEM triggers can be very minor. For some people it's walking for an hour; for others it's reading an email. Minor triggers can lead to major symptoms.
- PEM can also be set off by doing too many small, individually safe, things at once, or without enough rest between them.
- PEM symptoms may start straight after exertion but more often there's a delay of several hours or days between the trigger and the onset of symptoms - which can be very confusing.
- PEM recovery takes days, weeks, months, or even longer. There's even some evidence that spending too much time in a state of PEM increases the risk of long-term deterioration.

Remember that you can find more detailed information about PEM on our website (m.e.awareness.nz) and on dialogues-mecfs.co.uk (videos).



Pacing is a technique for reducing PEM; it's not a cure for ME. There is no evidence that Pacing improves ME itself (it only minimises PEM). However, there is some evidence that *not* Pacing may worsen ME.

The advice in this article stresses the importance of avoiding PEM as much as possible. That's the goal of Pacing after all. However, even with the best Pacing there will be times when PEM happens - *and that's no reason to panic*.

Yes, *occasional* episodes of PEM can be anything from highly unpleasant to very disabling - but they are unlikely to do permanent harm. As long as your ME is stable or even improving overall, over time, you're doing ok.

On the other hand, *frequent* or *constant* PEM, or *severe* PEM following major overexertion, are all much more risky. Many people with ME report that they never recovered back to their pre-PEM level after such episodes and advise erring on the side of caution.

PACING - BASICS

There are as many ways to pace as there are people with ME. That's because there is only one fixed rule, the rest is observation plus trial and error.

The fixed rule is simple: at any given time do not spend more energy than you have - and depending on the severity of your ME that may be very little.

Many analogies have been developed to illustrate the concept, with names such as staying within one's Energy Envelope, broken battery, energy dollars, spoon theory, and more. The essence of them all is that you have a limited amount of energy and you have to be careful how you spend it. Overspending is punished by PEM.

THE GOLDEN RULE OF PACING IS: DON'T SPEND MORE ENERGY THAN YOU HAVE.

The two key steps to Pacing are:

1. Observe:

- What sets off PEM? What types of activities? How much activity? And how much rest between activities helps prevent PEM?
- This step is described in the next section "Finding your Energy Envelope".

2. Adapt:

- Prioritise what you need or want to do. Figure out how to do things in ways that require less energy. Include resting periods.
- This step is described in the section "Chop & Change & Mix it up" (pp.12-15).




Doing everything in an energy-efficient way means you can do more overall.

FINDING YOUR ENERGY ENVELOPE

WHAT ARE YOU ABLE TO DO SAFELY?

WHAT SETS OFF PEM?

Finding your PEM triggers and your Energy Envelope requires trial and error. It can feel complicated at first but there are tools to help. The aim is to develop a good 'feel' for what you can and cannot tolerate. This is an ongoing process. ME and your Energy Envelope can fluctuate, which can be confusing, but regularly using some of the tools described can help. Everybody has different PEM triggers. Here we look separately at physical exertion, mental exertion, social interaction, emotional energy and environmental factors.

 **In real life one trigger rarely comes alone. A simple phone call requires physical exertion (muscles for talking), mental exertion (thinking), social interaction (another person to relate to), possibly emotional energy (depending on the topic), and maybe also environmental factors (background noise) - all of which take energy. For Pacing we are interested in the total, cumulative effects of all those different energy uses.**

Physical Exertion: This doesn't just mean exercise. It also means ordinary daily activities like brushing your teeth, talking, or standing upright. If you're using a muscle, you're using energy. Wearable devices can help you understand your physical activity better (see the section "Tools & Techniques" on pages 8-11).

Observe: What physical activities can you do, for how long, and how often, without setting off PEM?

 **Is there a time of day that works better for you?**


Mental Exertion: Your brain uses a lot of energy. Thinking, planning, remembering, studying, reading, writing, messaging, watching videos - it all uses energy. Which means it can set off PEM.

Observe: What mental activities can you do, for how long, and how often, without setting off PEM?

 **Be aware of the cumulative effect of exertion: the energy demands of several activities done without enough rest in between all add up.**


Emotional Energy: It takes energy to feel strong emotions. Which means they can set off PEM - yes, even happy emotions can do that. Of course you can't avoid having emotions, and many emotions are desirable or necessary parts of life - and that includes sad or angry emotions. However, some emotions are just unhelpful energy thieves and those are best avoided where possible.

Observe: What effects do different emotions have? Which ones are unhelpful?
Can you avoid the unhelpful ones or dampen them down so they use up less energy? Can you space out events you expect to be emotional?

 **Energy Envelopes fluctuate. They can get smaller when you have an infection, or when you already have PEM, and sometimes they change for no apparent reason.**

Environmental Factors: Many outside factors can increase the amount of energy your body uses. Which means they can set off PEM. If it's hot your body uses energy to cool down. If it's noisy your brain uses energy to filter out unimportant sounds. And so on.

Observe: What environmental factors affect you? Which ones are potentially avoidable?

 **Sometimes it's impossible to identify a PEM trigger. That's ok, no one can identify all of their triggers. Just try to identify as many as possible.**

Social Interaction: Socialising requires energy, no matter how much we love the person we are with. Which means social interactions can set off PEM.

Observe: How much time can you spend with other people, and how often? Does it make a difference how many people there are, who it is, or where you meet? What takes least energy: meeting in person, talking on the phone, with or without a video link, emailing, texting or messaging?

Resting & Recharging: This is an essential part of Pacing.

Observe: How much rest do you need to recover from different activities? Over time, do you feel better with a few longer rests or frequent shorter ones? What is most restful for you: darkness, silence, gentle music, aromatic oils, etc? Are there specific periods when you need more rest, e.g. at certain times during the menstrual cycle or during a growth spurt?

 **What level of activity can you maintain consistently, every single day, without setting off PEM?**

TOOLS & TECHNIQUES

TO FIND YOUR ENERGY ENVELOPE TO STAY WITHIN YOUR ENERGY ENVELOPE

The tools and techniques have two aims:

1. To help you get to know your own abilities and limits better so you can make better decisions.
2. To help you manage your energy better.



Not all the tools and techniques will suit all people. Just use the ones that work for you.

Activity & Symptom Diaries

A diary can help identify what you can do safely and what sets off PEM, especially if you have a delay between your PEM triggers and symptom onset.



Some people also learn to identify subtle early warning symptoms that tell them it's time to rest. However, not everybody gets those early warning signs.

Keeping an activity & symptom diary can be done on paper, on a spreadsheet, or with an app. Keeping a diary is energy-intensive and not a long-term option for everyone. It can still be a useful exercise to do for a few weeks to help you spot your own patterns.



Example work sheets can be found here, but you can make up your own: Solve ME/CFS PEM-Avoidance-Toolkit <https://solvecfs.org/wp-content/uploads/2019/01/PEM-Avoidance-Toolkit.pdf> (pp. 8-12).

There are many apps available (search for "symptom tracker"). Few are specifically designed for ME but general symptom trackers can usually be adapted to suit. It may help to discuss options with experienced users in an ME support group or forum. At a minimum an app should:

- be convenient to use,
- let you define what you want to track,
- and let you see potential connections between tracked events over several days.

Step Counters

A step counter (pedometer) can be a useful guide to your physical activity and give you a warning when you're getting close to your limit.

Some points to be aware of:

Despite the name most step counters don't count actual steps. Instead they analyse body movements to estimate a step count, and different models do this in different ways. Some models count "steps" when you move your arms, others do not. This doesn't matter much; it still gives a good estimate of your overall physical activity. Comparisons between your own readings and those of other people are likely to be misleading, however, and if you're getting a new model it may record differently from your old one, too.

The number of steps per day is only one indication of exertion. It doesn't account for other types of energy used. For example, you may not be able to manage your usual number of steps on a hot day or when you have to do more mental work than usual.



Use a step counter to keep track of your overall physical activity.

The total number of steps per day is only part of the equation. The other part is knowing how many steps you can take in one go.

For example, you may find you set off PEM if you take 1000 steps in one go. But if you only take 50-100 steps at a time you may be able to tolerate 1500 steps/day in total. Spreading your activity out over the day often gets you further.



Use a step counter to make sure you spread your physical activity out over the day.

Heart Rate Monitors - Basic Use

A heart rate (HR) monitor can help you estimate how energy-intensive a physical activity is and give you a warning when you're getting close to your limit. In some people HR also increases a lot with strong emotions and a HR monitor can help alert to this.

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Some people with ME find HR monitoring helps them a great deal with Pacing their activities, other people find other methods more useful.

There are many different types of HR monitors and with new models released frequently, each with a different set of features, this can be confusing. Consider joining a dedicated online forum for HR monitoring to discuss the pros and cons of the latest models and how best to use them specifically in ME. At the time of writing the closed Facebook group "ME/CFS - Pacing with a Heart Monitor #2" had good information and was well moderated. But if that doesn't suit you, you should be able to find alternative options.

Some points to consider when choosing a model:

Accuracy: This is getting better all the time but not all models are equal and in some models the displayed HR lags behind the actual HR, giving you a misleading reading. Many online tech sites test and review accuracy.

Convenience & comfort: Chest straps are generally more accurate but wrist or arm bands are more convenient and comfortable and thus more likely to be worn consistently. Some chest straps need a phone nearby while others connect to a wristband. Some wristband displays are too small to be easily read without reading glasses.


Features: Is the device waterproof? Does it allow you to set an audible or vibration alarm when you exceed a certain HR? Do you want basic HR monitoring or additional features such as resting heart rate, heart rate variability, sleep tracking, etc. (see HR monitors - advanced use on p.11)? More features often cost more.

The connection between HR, PEM & Pacing


Heart rate is an indicator of how much energy you're using during different physical activities. So the most basic use of a HR monitor is simply to observe which activities use the most energy. The higher the HR, the more energy you're using and the more likely you are to set off PEM. Once you have identified a high-energy activity you can try to find lower-energy ways of doing it.

 **Tip: Lifting your arms is energy-intensive. Save energy by keeping your elbows pinned to your sides and working with your forearms only, where possible.**

Example: Say you find standing in a hot shower (be sure your monitor is waterproof!) raises your HR a lot and sets off PEM. You can try a few different ways of having a shower. Does sitting on a shower stool help? A shower chair with back support? Cooler water? Only having a shower every third day? Etc.

 **HR can be affected by some heart medications as well as by having another condition such as Postural Orthostatic Tachycardia Syndrome (POTS). In this case HR monitoring is more difficult but it can still give you valuable information about what level of HR you can tolerate and what level sets off PEM.**

Quick guide to basic Pacing with HR alarms

 **If your HR monitor has an alarm, use it to help you stay below your upper HR limit, measured in beats per minute (bpm).**

1. Estimate your upper HR limit.


This is only a starting guess. Be prepared to adjust it later based on how your body reacts. Also review your HR limit if your ME becomes much more, or much less, severe for a sustained period of time.

The simplest way to make that first estimate is to start with a HR of 100 and see how it goes. Other common methods used by experienced patients and clinicians to estimate upper HR limits are:

- For mild ME, calculate: 220 minus your age, then multiply the result by 0.6.
- For moderate ME: 220 minus your age, then multiply the result by 0.5.
- For severe ME: measure your RHR every morning for several days to get an average, then set your HR limit at your average RHR+10.

Example [age 40, mild ME]: step 1) 220 minus age 40 = 180, and step 2) now multiply 180 by 0.6 = 108 bpm

2. Now set your HR monitor alarm to your estimated HR limit (e.g. 108 bpm).

 **It's impossible to always stay below your HR limit. This doesn't matter if you don't go over your limit for too long, ideally no more than a few minutes at a time. A few people even report positive effects from raising their HR occasionally for a couple of minutes only (no more than that, and for others this doesn't work at all). But as a general rule, when the alarm goes off because you've exceeded your HR limit, stop what you're doing and rest as soon as safely possible, even if it's inconvenient.**

3. Observe how your body reacts over time.


Do you get PEM more or less often or severe?

4. Adjust your HR limit based on your observations.

If you never set off PEM by staying below your estimated HR limit most of the time, the estimate may have been correct - or it may have been too low and you may be able to tolerate more activity. Try increasing your limit a little, only by a few bpm at a time, to see if you can tolerate a higher level. But if at any time you set off PEM, reduce the HR limit again. Don't test your limits too often, only if you've been stable for a while or think your ME is improving.

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If you still set off PEM despite staying below your estimated HR, the estimate may have been too high. Lowering it further may help. However, HR alarms don't work for everybody and some people with ME, especially severely affected ones, find it impossible to set a "safe" HR limit. But even without a "safe" HR limit it is a good idea to avoid peaks of exertion and a HR alarm can help alert you to them.

 **Some people disable their HR alarms because they find them too stressful. That's ok. You can still keep an eye on your HR by looking at your device often.**

Heart Rate Monitors - Advanced Use

Resting Heart Rate (RHR) & Heart Rate Variability (HRV) are linked to overall health status. In ME, any sudden change - up or down - can be one of the earliest signs of PEM. Extra rest at this point usually doesn't stop the PEM but can limit how bad it gets.

 **Track RHR and/or HRV over time to learn what is normal for you and what types of changes signal PEM for you - it's individual.**


RHR - Resting Heart Rate

This is simply the number of heart beats per minute, measured at rest. You don't even need a device for this; you can take your RHR by feeling your pulse with your fingers and counting the beats for 1 minute (search Youtube for instruction videos). If you measure RHR by hand you need to figure out a way of keeping records of the results, be that on paper, computer or using an app. Or you can let your HR monitor and its app do the counting and recordkeeping for you.

HRV - Heart Rate Variability

This feature is typically only found on the more expensive HR monitors. HRV measures the tiny natural variations in time between two heartbeats. A good HRV is linked to overall health; counter-intuitively a higher HR variability is generally better.

RHR and HRV are affected by many factors, e.g. food, drinks like coffee and alcohol, exercise, temperature, and more. To minimise the effects of those factors, readings are best taken at the same time each day, after a short rest and when you're relaxed. Most healthy people do them first thing in the morning but some people with ME have a more erratic HR then so should choose a time when their HR is more stable.

 **Tools are just that: tools. They can help you understand your individual Energy Envelope. And they can help you stay within that Energy Envelope. But you can practice Pacing without any tools, and many people do.**

PACING - PRACTICE

CHOP & CHANGE & MIX IT UP

- Chop out unnecessary energy demands
- Change the way you do things
- Mix up rest and different types of activities



All examples given in this article are just that: examples. Your individual situation will vary depending on the severity of your ME.

CHOP - Give any unnecessary energy demands the chop

Do you really need to do this at all? There are many things we do out of habit or to keep up appearances - and not all of them are strictly necessary. An energy-sapping hot shower can often be replaced by a baby wipe.

Do you need to do it now? If your house is burning, yes, get out now. Most other things can be put off until you have more room in your Energy Envelope.

Do you need to do all of it? There's no rule that says a grocery delivery (because of course you have arranged for groceries to be delivered) has to be put away immediately, or at all. Yes, any chilled items need to be kept chilled but anything else can be dealt with later or be used straight from the delivery bags.

Do you need to do it? Delegate. Ask for help. Accept offers of help. Family, friends, colleagues and neighbours may even be grateful to have something practical they can do for you. It's win-win: you get a helping hand and they get to feel good about themselves. Also check with your GP and relevant social or welfare service organisations such as Work and Income NZ (in NZ) if you're eligible for any services such as home help or meal delivery.



You can do whatever activities you like - just as long as they don't set off PEM.

CHANGE the way you do the things you need - or want! - to do

► **How can you do this activity differently, so it takes less energy?**

For example: Can you sit instead of stand, lie down instead of sit, use wheels instead of your legs? Can you do the activity more slowly and gently?

Occupational therapists know a lot about energy-saving strategies and it may be helpful to consult one if they also understand ME (not all of them do - see the Myths section).

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...CHANGE the way you do the things you need - or want! - to do, continued

Consider mobility aids such as a stairlift, scooter, electric wheelchair, walking frame with a seat, or a disability parking permit. While that's a big mental adjustment it's worth weighing up the pros and cons in your specific situation. It's a pragmatic assessment of how best to use what little energy you have, not a question of giving up - whatever other people say. Do you want to use up all your energy just on walking, or use a wheelchair and have enough energy left to enjoy a chat with a friend?

► How can you achieve the same goal, but in a different and easier way?

For example: You need groceries but shopping is too exhausting - get them delivered instead. You want to keep up with your movie-going friends but going to the cinema is too exhausting - get them to come to your place instead and stream a movie. You want to keep up with the news but reading or watching TV is too exhausting - use audio instead (such as radio, podcasts or text-to-speech software).



Take a problem solving approach. This puts the focus on the things you can do - albeit differently - not on the ones you can't. It also gives a sense of achievement when you have figured out an ingenious, energy-saving new way of doing something.

► Can you adjust your environment?

For example: Coping with physical discomfort takes energy. How can you avoid uncomfortable temperatures, noise levels and lighting?

For example: A well organised house saves energy. Place all frequently used items where they're easily accessible. Place chairs in strategic positions (by the kitchen bench, by the bathroom vanity, in the shower, on the landing of the stairs, etc.). Move your bed into the living room or nearer to the bathroom. Install handrails or a stair lift.

MIX it up: Task switching, resting & pre-emptive resting

► Alternating different types of activities is called task switching

This makes use of the fact that different activities use energy differently. Alternating between short periods of physical and mental activities can be less exhausting than doing a single activity for longer.

For example: You may not be able to read a whole article in one go. But you may be able to read half of it, do a small physical task to give your brain a rest, and then return to reading your article.

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Note that task switching is better suited to mild ME, those more severely affected will also need rest between each activity.

► Rest & recharge before running out of energy

Resting is an essential part of Pacing. There are different ways of resting. It takes some trial and error to learn what combination of the different types of resting is right for you, and how much rest you need.

- You can take flexible rest breaks between activities as needed. Depending on your severity you may need to break activities up into smaller tasks with rest in between. You don't have to finish a job before taking a rest. For example: To have a meal start with partially preparing the food. Rest. Finish preparation. Rest while the meal is cooking. Eat. Rest. Tidy away. Rest some more.
- You can build regular, scheduled rest breaks into your daily routine. Having a resting routine makes it easier to remember to rest, especially if your PEM symptoms only appear after a delay.
- You can do pre-emptive resting, which means resting in advance, before starting an activity. This ensures you start that activity with your maximum available energy, not half-way on the road to PEM before you even start. Pre-emptive resting is particularly helpful when you know you have an energy-intensive activity ahead of you, for example a visit to the doctor.
- Finally, there's resting to recover from an activity, or from PEM. The more you have exerted yourself, the more time you need to allow for recovery resting. Recovery resting means recovery back to where you were before the activity or before PEM; it doesn't mean recovery from ME. Resting is a very important part of Pacing but it is not a cure for ME.

 **Once you've run out of energy it's usually too late to avoid PEM but resting now will still help reduce the severity of PEM.**

► Having a good routine makes task switching & pre-emptive resting easier

Keeping track of all this chopping & changing & mixing it up can be overwhelming. If so, you may find it easiest to tackle one activity at a time, starting with the most energy-intensive ones. Once you've figured out a good way to deal with it, stick to it until it becomes a part of your routine. Then tackle the next activity.

 **Use a timer to help you to stick to your plan. When it beeps it's time to switch tasks or to rest or for your visitors to leave.**

Of course non-routine activities, like going to the doctor, are necessary at times. In this case it's a good idea to rest extra in advance and to drop other activities from your usual routine to compensate for the extra energy demand.

 **Routine is your friend - but keep it flexible.**

Pacing and Employment or Education

Many people with ME have to give up employment or education, or significantly reduce the hours they can spend on it. This is one of the major decisions people with ME have to make, with big implications financially, socially and emotionally. This may be why many people with ME report regretting not stopping or cutting back earlier: the decision is a difficult one. But if your ME is mild enough for you to continue at work or in education, the chop and change and mix it up Pacing principles described above apply to work and education, too. The complicating factor is that you will have to discuss your needs with your employer or your institution. They should make an effort to accommodate you and if you're lucky they will be supportive. But be prepared for the possibility that they won't be. You may have to educate them or even fight for your rights. If so, get support from patient organisations. Fighting on your own while also trying to pace is too difficult.

Pacing and Children

Pacing takes a lot of planning and discipline - not the first words most people associate with children, especially young ones. Regardless, the chop and change and mix it up Pacing principles described above apply here, too, but clearly Pacing becomes a whole lot harder when there are children involved. Seek and accept any help and support you can get.

► [You have ME and are considering whether to have children at all.](#)

This is one of those big life decisions only you can make. However, if you haven't had ME for very long it would be a good idea to put off the decision until you have more experience in living with ME. Here are some other points to consider. Being pregnant, looking after a baby, and later a child, takes a lot of energy so you'll need to drop a lot of the activities you currently do to balance out your energy budget. Will you be able to do that? Will you still be able to do that if your ME gets worse? Do you have enough reliable, long-term support people to help you?

► [You have ME and are already the parent of one or more healthy and energetic children.](#)

Much depends on how severe your ME is, and on the ages and personalities of your children. Some parents with ME can pace quite well (with help from others) while also being able to spend a lot of quiet time with their children. Others need to make significant adjustments. If you struggle to pace as much as you need to, look for any way you can get the kids out of the house and/or looked after by others for periods of time. Babysitters, kindergartens, after-school programmes (with healthy parents of classmates doing the taxi service), staying with extended family or school friends are all responsible and loving ways to temporarily get rid of your kids. They can be kids without having to worry about wearing out their parent, and you can get some rest and maybe even do some of the many extra tasks parenthood brings with it - but delegate as many of those as you can, too. The more rested you are for the time you do spend with your children the more you can enjoy each other. Quality time beats quantity in this case. continues...

► Your child has ME

Convincing a child to pace is challenging and the delayed onset of PEM makes it even more difficult. Younger children don't fully understand the connection between playing now and feeling much sicker tomorrow. Older children, especially during a rebellious phase, may refuse to accept the connection. You won't always succeed at getting them to pace but you can create an environment that supports Pacing.

Depending on their age and severity, you can for example create a daily routine including lots of rest. You can limit screen time. You can arrange a suitable - reduced - school schedule. You can educate their friends and their friends' parents about how to behave during a visit so they take responsibility for initiating low-energy activities and for not staying too long, taking those decisions out of your child's hands.

► You have ME and are also the parent of one or more children who also have ME (or another serious health condition), or you have other dependents such as frail parents to care for

Maybe more than anyone you need to apply the chop and change and mix it up Pacing principles described above. And also more than anyone do you need to seek and accept any help and support you can get.

WHAT TO DO WHEN PEM STRIKES

PEM can happen to even the best of pacers. Maybe you simply miscalculated and that 15 minutes on the phone you thought was going to be ok was too much after all. Maybe you made a conscious choice and decided opening the Christmas presents with your children was worth suffering a week with PEM for. Maybe something unexpected happened, like a burst water pipe, and you had to spend more energy than expected.

Whatever the cause of your PEM, the most important goal now is to minimise how bad it's going to get. Cancel any plans you can possibly cancel and plan on extra rest instead. The sooner and the more you can rest the better.

How soon should you rest? Ideally as soon as you realise you have overexerted. Yes, even before any symptoms appear. With delayed-onset PEM it can be tempting to continue until you start having symptoms but in doing so you risk getting much more severe PEM later on. Running on adrenaline can have the same effect. It allows you to push through your symptoms for a little while but at a cost: you'll end up with PEM on top of PEM.

How much should I rest? This varies depending on how severe your ME is but in all cases it means resting more than you normally rest - and probably much more than you think.

Even people with relatively mild ME may need bedrest during PEM.


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How long do I need to rest extra for? This varies depending on how severe your PEM is. It could be days, weeks or months. The main guideline is to wait until your symptoms have returned to their usual level before gradually(!) returning to your normal routine. It takes time for your Energy Envelope to return to where it was before PEM. In very severe cases of PEM it may never return to that point, which is why it is so important to avoid severe PEM.

After an episode of PEM it's a good idea to review what happened. Is there anything you could do differently next time to avoid or minimise PEM? Could you be better prepared, for example by having more ready-to-eat food handy, or a contact list of people to call on for help?

STAYING SANE THROUGH IT ALL - WITHOUT STRESSING (MUCH) ABOUT STRESS

Stress and worry are a part of life. Having a chronic illness can add to this, that's only natural. Consider joining a patient support group, in person or online, where you can talk about your worries and challenges with other people in the same situation. However, if you feel excessively anxious or depressed, and are struggling to cope, seek professional help (ideally from a health professional who understands ME, not all of them do - see the Myths section, p.24) or use the helplines and e-support services in your country.

 **Stress and worry by themselves don't cause ME but they can make you feel worse because they are big energy sappers and as such they are something you want to reduce as much as possible.**

In principle much of the usual advice on how to reduce stress applies to people with ME, too, but in practice it doesn't always work. Ironically, trying to follow stress reduction advice developed for healthy people can create more energy-sapping stress for someone with ME.

 **Any energy spent on needless worrying can't be spent on something better.**

► Common stress reduction advice - eat a healthy diet

A great aim to have but meal-planning, buying ingredients, and meal preparation all take energy and can themselves become a source of stress. It's ok to just do the best you can on any given day. Patient support groups often exchange handy energy-saving tips. And stocking your freezer with ready-to-heat, healthy meals is something you could suggest to anyone asking if there's anything they can do to help.

► Common stress reduction advice - get enough quality sleep

Another great aim to have, especially if you have mild ME and are trying to function on a normal work or school schedule. With ME getting the recommended 7-9 hours sleep per night can be difficult to achieve though. Much of the usual sleep hygiene advice is worth trying, e.g. no screens or coffee close to bedtime; a cool, dark bedroom; and a quiet, non-stimulating evening routine and a regular bedtime. Exercise during the day is often advised, too, but this is not suitable for most people with ME.

Many people with ME find that the usual sleep hygiene advice is not effective enough. ME can disrupt normal sleep patterns - and PEM even more so. You may find you need much more sleep than when you were healthy, and even more sleep when having PEM. Or you may have the opposite problem and struggle to get enough sleep. This is often a sign that you need to rest more during the day to be able to sleep at night.

Feeling tired-but-wired can be a sign of PEM and that you need extra rest and sleep. If the usual sleep hygiene advice plus extra rest is not helping you enough, you may need to talk to your GP about sleep medication.

► Common stress reduction advice - meditate (or similar)

Meditation, mindfulness, breathing exercises, etc. are all excellent techniques to reduce stress - if they work for you. If you find them too exhausting because of brain fog, or they just don't help, there may be other ways of calming your mind that suit you better, like listening to quiet music, watching birds, observing patterns of light, or something else altogether. Whatever works for you.



If you have ME it's only a matter of time before somebody tells you mind-body techniques can cure you. Ignore them, they don't understand ME.

► Common stress reduction advice - exercise to lower stress

Many people with ME don't have room in their Energy Envelope for exercise. If that's you, just ignore that piece of advice, it's not right for you. If your ME is mild enough to allow you to do some exercise, the Workwell Foundation has advice on how to do so safely.

► Common stress reduction advice - stay socially connected

This can be difficult for people with ME, for two reasons.

One, all social interactions take energy so you may have to find new, lower-energy ways of keeping in touch with family and friends. Face to face and telephone conversations tend to be the most difficult because they happen in real time. Many people with ME find emailing, texting and messaging take less energy. Remember other people can't guess your needs so expect to have to spell them out.

Two, some of the people in your life may be unsupportive and not (want to) understand ME, which can be a major source of stress, for all concerned. Remember that this isn't about you; it's about their own attitudes and insecurities.

One strategy is to gently but firmly state your specific practical needs for a specific occasion. No lengthy explanations or entering into a discussion about it, just a short "I look forward to your half-hour visit but when the timer buzzes I need you to leave", for example. It's up to the other person to respect that. If you do this consistently many people will respond positively, eventually. If they don't, and it's causing you too much stress, you may have to make the hard choice to minimise contact with that person if you can.

Consider joining a support group, in person or online, where you can be part of a community and where you can freely discuss ME-related worries (as well as other things). You will be less reliant on emotional support for ME issues from those close to you. Getting your ME support from a support group may even improve your relationship with the people in your life who are not so understanding of ME; you can focus more on matters not involving ME with them.



Support groups are a great way to connect - but only if you and your group are a good fit. The "wrong" group can be a source of stress.

► Common stress reduction advice - do something for others

We all like to help and be useful but with ME you won't be able to do all the things you used to do for others - and you may feel bad or guilty about it, which is stressful in itself. However, there often are small things you can do for others that won't rob you of all your energy but that will be highly valued by the receiver. A kind and thoughtful comment or message goes a long way for example.

You can also turn the advice around and give others the opportunity to help you. For example, others can help you spot the signs when you've overdone it and tell you to rest.

- ▶ Common stress reduction advice - don't sweat the small stuff, stay curious, enjoy the small things in life

Having ME can be an overwhelming experience, making it difficult to follow this advice, especially if your ME is very severe - but these are low-energy ways to help keep stress at bay and are worth trying. As with anything, if you find doing these things creates more stress or even PEM, they're not for you.



Do the best you can with the resources you have at the time.

- ▶ Common stress reduction advice - do something creative

Many people with ME find doing something creative helps them keep their sanity. But because of their limited energy people with ME have to get creative about being creative. Whatever you want to try has to match your energy level - you don't want to set off PEM.

Art and craft are obvious examples of creative activities but not every person with ME has enough energy for that. Less energy-intensive examples are creating short texts or pieces of music. Computer-aided design may be an option, or you could think up a new recipe (for somebody else to test). If any physical movement is too much, you may still be able to do some creative visualisations in your mind.

Whatever you choose, either do small projects or, if you're patient, larger projects divided into small parts. People with ME have written books one sentence at a time (you don't have to be that ambitious!). Importantly, don't forget to rest, it's easy to get carried away when doing something you enjoy. Use a timer if you need to.

- ▶ The Internet and stress

The Internet is a great source of information, support and social contact - and of fake news, false support and negative social experiences. None of which is unique to ME, but having a chronic illness can make you more vulnerable. For example, you'll encounter plenty of false hope being peddled in the shape of unconfirmed "recovery" stories, often selling this miracle cure or that snake oil.

You may face pressure to try X or Y, and if you don't try X or Y, you may well be accused of not making an effort to get well. This is all nonsense - when the real cure for ME comes you will hear about it through reputable channels and it'll be big news, you won't miss it. But until then the false hope roller coaster can be a stressful experience.

It's a good idea to lurk for a while in groups and forums to get a sense of their culture. If they make you feel guilty or inadequate, leave and find another one that makes you feel supported.



**Learn to spot mis- and disinformation and ignore the false hope peddlers.
Remember that if it's too good to be true it very likely is.**

PACING MYTHS AND OTHER CONFUSIONS







► Name Confusion

Various Pacing techniques are used in many illnesses but not all versions are suitable for ME. Confusingly the names are often similar. Here's an incomplete list of names frequently confused with Pacing for ME: graded exercise therapy, graded activity, pacing up, adaptive pacing, activity management, balancing activity, energy management, and more.

The various techniques have some common elements but there are also important differences.

Typically they all start something like this: First find the level of activity at which your symptoms are consistently stable; reduce your activity level if necessary. Avoid a push-crash pattern where you do too much on a better day only to crash later as a result.

After this first phase Pacing for ME becomes different from other types of pacing (whatever their name). The key points are summarised below.

Unsuitable types of Pacing [names vary] (after the initial stabilising phase)	Suitable Pacing for ME (after the initial stabilising phase)
 Once stable, increase your activity in small steps and at regular intervals. Often you are given a prescribed exercise programme.	 Once stable - and only if you suspect your ME may have naturally improved - increase your activity a little on one day as a trial. Then wait to make sure you don't get PEM before repeating.
 Intended outcome of the repeated activity increases: increase your fitness and your tolerance for activity (this does not work in ME!).	 Intended outcome of any very occasional one-off activity increases: explore the boundaries of your Energy Envelope.
 If symptoms increase, ignore them and continue with your programme of regular activity increases.	 If symptoms increase, do NOT ignore them but reduce your activity back to a level that doesn't set off PEM.



Not all healthcare professionals know the differences between the various Pacing techniques. Compare their "Pacing" advice to the table. If it looks more like the red side of the table it's a warning sign you're being recommended the wrong type of Pacing. Any Pacing advice for ME should look more like the green side and should always aim to avoid or reduce PEM.

- ▶ Confusion: Many websites say Pacing includes increasing activity by 10% at a time

There are two types of websites advising this. The first are websites promoting unsuitable types of Pacing (see table) that reflect outdated ideas about ME. Unfortunately even some ME websites still do this.



Red flag: if the recommendation is to keep increasing activity even if you get PEM as a result, it's not a type of Pacing suitable for ME.

Other websites advise a 10% increase only as a way of testing the boundaries of your Energy Envelope. They recommend that you are guided by your symptoms: if you get PEM, pull back. No need to be precise about 10% by the way, just keep any activity increase very minor.

This second approach is compatible with ME but **note that you should only test the limits of your Energy Envelope if you've been stable and without much PEM for at least several weeks - preferably months - and you feel your ME has naturally and lastingly improved** (something that doesn't happen for everyone). Also, "improvement" can be deceiving. If you're Pacing well you will likely feel somewhat better simply because you experience less PEM - that's the goal of Pacing after all - but this does not automatically mean your underlying ME has also improved.



If you do want to test if your Energy Envelope has increased, do so very slowly and carefully and be prepared to reduce activity again if you experience any PEM.

- ▶ Myth: Pacing can improve ME (not just PEM)

Probably wrong. There is no evidence Pacing can improve the underlying disease ME itself. What Pacing can do is reduce how often and how severely you suffer from PEM on top of your usual ME symptoms. There is also some evidence that people who do not pace are at greater risk of getting worse over time.

- ▶ Myth: To get better you have to work on increasing your activity level

Wrong. If you're currently playing it very safe and you aren't setting off PEM, you may - possibly - be able to increase your activity level a little bit at a time within your Energy Envelope. But going above the upper limit of your Energy Envelope too often or too much is not going to make you better. On the contrary, it will set off PEM and risk making you worse over time. In fact some ME doctors recommend doing only roughly 60% of what you think your Energy Envelope allows you to do, to be on the safe side. Planning on doing only about 60% means a) you have room for error, and b) you have a little bit of spare capacity should something unexpected crop up.

► **Confusion: If I don't work on increasing my activity level, how do I ever get better?**

ME is a naturally fluctuating disease and many people with ME experience a degree of spontaneous improvement at some point during their illness. Pacing and staying within your Energy Envelope while you're waiting for that to happen means you're ready to benefit if your ME does naturally improve. On the other hand, not pacing and not staying within your Energy Envelope means you're placing your body under constant stress and this could counteract any natural improvement.

If you are lucky and you are naturally improving, then - and only then - can you carefully increase your activity level to explore the new boundaries of your increasing Energy Envelope. But remember: any PEM, pull back.



Currently nobody can predict who will improve naturally, or when, and who will not. If you are one of the unlucky non-improvers: it's just bad luck and it's not your fault!

► **Myth: There's such a thing as a stable baseline**

Only partly correct. A stable, sustainable baseline of activity and symptoms - a level of activity that doesn't set off PEM - is a useful idea because it is the opposite of unhelpful push-crash or roller-coaster patterns where you do too much on one day only to crash the following days.

In reality a stable baseline is a moving target because ME is a naturally fluctuating disease. Many additional factors also play a role. How much you can do on a given day without setting off PEM depends on things like how much you did on previous days, whether you're coming down with a cold, how you slept, where you are in your hormonal cycle if you're a woman, or maybe the weather is particularly energy-sapping.



A perfectly stable baseline isn't possible but a more stable, more sustainable baseline is. Importantly, it leads to less PEM.

► **Myth: People with ME crash because of boom & bust activity patterns**


There's no evidence for that. Surveys show that most people with ME intuitively develop stable activity patterns without major peaks. Boom & bust suggests a very high level of activity like partying the night away without thought for the inevitable hangover the day after. That's not the behaviour of a person with ME.

What people with ME do at times is push & crash. They push past their energy limits either because they have no choice, say for a visit to the doctor. Or they push through because they choose to, say for an important family occasion. But they try to push as little as possible in the circumstances because they know very well that their push will lead to a crash.

► **Myth: Pacing is unsuitable for people with severe ME**

Wrong. It is true that people with severe ME can exceed their Energy Envelope simply by being exposed to light, by sitting up in bed, or by speaking a few sentences. This can result in "rolling PEM", a state of constant PEM.

Not all of the suggestions in this article are suitable for very severe patients but some are relevant. The total amount of PEM you suffer can still be reduced by applying the core principles of Pacing: eliminating all unnecessary energy use and spreading out any essential tasks, such as eating and personal care, over the course of the day with rest in between.

 **For severe ME patients it is especially important that the people around them understand Pacing so they don't - with the best of intentions - overload the patient by trying to help with too many things at once, for example by helping the patient in the bathroom then, without a rest, giving them a meal, all while chatting non-stop. The patients themselves often won't have the energy to explain Pacing, so it's up to the carers to take responsibility and learn about Pacing.**

► **Myth: Health professionals know how to help with managing ME**

Only partly correct. Some do know. But many don't. Many doctors, nurses, physiotherapists, occupational therapists, psychologists, etc. have never received any training about ME. Others were taught information that's now outdated - they act in good faith but don't always know their knowledge isn't up to date.

It's only recently that biomedical research has changed best practice recommendations for ME and many health professionals have not been able to catch up - and a few are also unwilling to do so. However, many are willing to learn and work alongside their patients.

 **Health professionals may find the Resources (p.27) section helpful.**

► **Confusion: So exercise is always bad for ME?**

Not always. It depends on how you define "exercise" and on how severe your ME is. If you have ME it's best to define "exercise" as any movement intended to improve health, which could be a walk or a single, gentle stretch.

The basic rule of Pacing applies to exercise as it does to any other activity. Exercising *within* your Energy Envelope is probably helpful, just like it would be for a person without ME. But exercising outside your Energy Envelope is unhelpful.

continues...


...Confusion: So exercise is always bad for ME?, continued

If your ME is **mild**, you may be able to do a little bit of regular walking, swimming or other exercise and gain all the benefits regular exercise gives. Just keep it at a level where it doesn't set off PEM.


 **The key, as always, is staying within your Energy Envelope. The physiotherapists from the Workwell Foundation have good advice on exercising with ME (see Resources p.27).**

If your ME is **moderate**, and those sorts of aerobic exercise are too much for you, you may still be able to do *very short* bursts (seconds to a few minutes) of strength or resistance training. This tends to be better tolerated by people with ME than aerobic exercise. Or try *very short* sessions of pilates, yoga, tai chi, etc. at home (no travel). You may not get the full range of exercise benefits but you can still maintain some of your strength, balance and flexibility, all of which are beneficial to overall health.

Don't forget to plan in rest periods when exercising. The physiotherapists from the Workwell Foundation recommend allowing 3 minutes of rest for every minute of exercise, so if you exercise for 2 minutes you should then rest for 6 minutes before attempting anything else.

 **If being upright sets off your PEM, there are adapted versions for people who need to do their exercise sitting or lying down.**

If your ME is **severe**, your exercise options are very limited but you may be able to do a very little gentle stretching to maintain some flexibility. This may help reduce painful stiffness.

 **Activities of daily living are also a form of exercise. If you have to drop such activities in order to fit in formal "exercise", how much do you gain and is it a worthwhile trade-off for you?**

► **Myth: Rest means doing absolutely nothing**

Many ME websites advise this and it is true that lying in a dark room without stimulation and no activity of any sort uses the least energy. It's definitely a good way to rest but it's not the only one.

What type and amount of rest you need is individual and a less than perfect rest is better than no rest at all. For example, if you're away from home and there is no bed handy, it doesn't mean you have to give up on resting altogether. Better to look for the best available option, whether that's a chair in a quiet corner or a lie-down in the back of the car.

continues...

...Myth: Rest means doing absolutely nothing, continued

You may also find it difficult to do nothing at all because of pain or because worrying thoughts are running riot when you don't have any distractions. Resting itself then becomes stressful. In this case the best option is to find the lowest level of distraction that allows you to rest, for example meditation, relaxing music or easy audiobooks or podcasts (but avoid a lot of suspense in the plot).

Naps are another form of resting. Some websites advise against sleeping during the day on the grounds that it will stop you from sleeping at night and this is the case for some people with ME. Others need (much) more sleep than the standard 7-9 hours though, and some people with ME also have very disturbed sleep patterns. So if you find napping during the day helpful, it counts as resting.



Pacing is a practice - you learn it by doing. Practice makes perfect - or at least it makes you better at things - but even expert pacers get it wrong sometimes. That's life - it will interfere with your plans, so be prepared to be flexible.

SOME FINAL NOTES

The title of this article is *The Art & Science of Pacing*. In reality Pacing is mostly an art with just a little bit of science.

Studies have shown that PEM exists - you are not imagining it. They have also shown that graded exercise therapy - which is the opposite of Pacing - does not work.

And patient surveys and case studies have documented that, on average, people with ME who pace feel better than those who do not. They have also documented that a significant number of those who do not pace - especially those who try graded exercise therapy - get worse.

So science is telling us that Pacing is a good idea. But it doesn't tell us anything about *how* to pace. There simply are no studies to see whether heart rate monitoring is more effective than step counting, or whether many short rests are better than a few long rests. That's where the Art of Pacing comes into the picture. It could also be called the Trial & Error of Pacing. It amounts to trying out different Pacing strategies, carefully observing your body's reactions, and adjusting accordingly.

PACING RECAP

Pacing can reduce PEM. It cannot cure ME.

Understand your body: How does it react to different types of exertion?

Aim for a stable level of activity that doesn't set off PEM.

Prioritise important activities. Drop unimportant ones.

Adapt activities so they take less energy.

Break up your day with rest periods.

Don't spend energy you don't have.

SOURCES & RESOURCES

- General ME information (comprehensive): Centers for Disease Control and Prevention www.cdc.gov/me-cfs/index.html
- Overview of ME with focus on PEM (brief): Post-exertion 'Crash', not fatigue per se, marks syndrome by Miriam E. Tucker (Medscape 2016) www.medscape.com/viewarticle/871482
- Dialogues for ME/CFS videos (5-15 minutes) introducing ME, PEM and the problems with GET www.dialogues-mecfs.co.uk/videos
- Video animation on ME and PEM (3 minutes) provides insight into PEM and how it impacts the lives of those living with ME. www.youtube.com/watch?v=TGl01v7KVJQ
- Emerge Australia's brief guide to managing ME including Pacing www.emerge.org.au/treatment-and-management
- Article for clinicians (brief) on how the changing evidence for GET has led to GET no longer being recommended, and what to offer patients instead: <https://doi.org/10.1007/s11606-019-05375-y>
- Friedberg, F., Sunnquist, M. & Nacul, L. Rethinking the Standard of Care for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. J GEN INTERN MED (2019). doi.org/10.1007/s11606-019-05375-y
- Patient survey on treatment effects including harms (comprehensive): Effect of CBT and GET - patient survey results (Forward ME, Prof. Helen Dawes, Oxford Brookes University) for the NICE Guideline Development Group (UK) www.meassociation.org.uk/wp-content/uploads/NICE-Patient-Survey-Outcomes-CBT-and-GET-Final-Consolidated-Report-03.04.19.pdf
 - Summary of the above report (brief) www.meaction.net/2019/04/03/get-and-cbt-are-not-safe-for-me-summary-of-survey-results
- Workwell Foundation library of resources including video presentations and published research papers covering what "exercise" people with ME can and cannot do. <https://workwellfoundation.org/resources>

M.E. AWARENESS NZ

Mobilise | Educate | Advocate | Network

M.E. Awareness NZ is a national collective of People with ME and our carers and supporters. We exist to increase awareness of this debilitating disease and to improve the lives of those affected by it.



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