

Pacing for ME and CFS: a guide for patients
 by
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Introduction

Advice to pace activities is based on the observation that people with ME tire easily. It's one of the main characteristics of the illness. From the reports on people with Multiple Sclerosis, Parkinson's Disease and other medical conditions who also report profound fatigue, I thought that patients with ME might benefit from a similar approach. That was in the late eighties.

I'd had a post viral syndrome in the seventies but no one had mentioned pacing to me, nor had I read about it in the patient literature. I know that many of those affected learnt to pace themselves through trial and error, but that often took time. To avoid others wasting their time, and to prevent months or years of unnecessary relapses, I decided to put my ideas down on paper. Not long after, colleagues began to promote an alternative approach, namely that of graded exercise.

My initial advice was little more than a sentence or two, along the lines of 'do as much as you can within your limits'. That led to pertinent questions such as 'how do I determine what my limits are' and 'I'm always tired so how can I pace myself'? As a result of discussions with, and articles from Drs Ramsay, Dowsett and Ho-Yen, but also following suggestions from patients and critics, I gradually refined my advice.

The relevant research on ME was another influence, and provided a theoretical base as well as supportive evidence. Thus the concept of pacing developed from the experience of patients with various medical disorders, and my knowledge of ME and post-viral syndromes. The theory and studies, so important in these days of evidence-based medicine, came later.

Basic guidelines

The aim of pacing is to remain as active as possible but to avoid the relapses resulting from overexertion. As you improve (whether as a result of medication, other therapies, time or luck), your boundaries will increase and you will gradually be able to do more. If people want to increase their activity levels every few days, that's fine, as long as they remain, in the words of Dr Melvin Ramsay, "within the limitations which the disease imposes".



1. Stop before you overdo it

In practice, pacing means stopping an activity when you feel you have reached that point where pleasant tiredness becomes unpleasant, where arms or legs begin to feel weak, or where one starts to feel unwell or sick. Some might find it more helpful to rest at the first sign of muscle weakness, and then carry on. Dr. Ho-Yen wrote, "Learn to listen to your body. It will tell you when there is a problem". And I believe that too.

2. Limit activities each day

Pacing also means you limit activities per day, e.g. washing one day, ironing the next. And if you are bed-bound, it means pacing yourself on the telephone and surfing the net. However, if you are tired-all-the-time and you have no energy at all, then your doctor needs to reassess you. ME is a fluctuating condition, except during the most severe of relapses.

3. Plans can be abandoned

If you want to plan your activities for the whole day, that's fine. However, it's not part and parcel of pacing. Pacing does not require you to make plans and stick to them. It only requires you to stay within your limits and stop when your body tells you it needs to rest. On the other hand, you might be able to conserve some energy and pace yourself better if you plan ahead. For instance, you might write down activities per week, making sure you allow some space between the most tiring. If you still do the housework yourself, you could wash one day, Hoover the next. Also, try to include at least one day of rest after something particularly stressful or exhausting.

If you are severely affected, you may require three free days, or even a week or more. You'll know from experience how you tend to respond to various activities and what you can manage each day. Do note that plans are not the issue. You don't have targets or goals, other than to have some self-discipline and stop before you over-exert yourself. Making plans and attempting to stick to them belong with other strategies such as graded activity/exercise.



4. Reassess activities

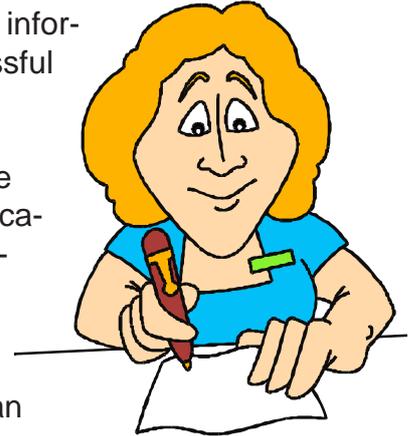
Another aspect of pacing involves finding ways to reduce activities.

For instance, washing up is important but drying it isn't. Why not let the plates etc. dry in a rack? Perhaps you can save a shopping trip a week by getting a neighbour to help? Maybe you can get some things via the Internet? If you

need tests in the hospital, you could ask to have them all during one visit. (Tip. Some hospitals only take blood in the morning. In that case, ask for an appointment during the morning. It saves you having to go back). And of course, 'never stand when you can sit'.

5. Keep a diary

Another component of a good management programme for ME, and an aid to pacing, is to keep a diary. Different specialists recommend different things. I advise patients to include information about stressful events and what they've eaten. It should also include details about medications plus any unusual or exacerbations of symptoms. In this way, the patient can determine if there are any patterns. Most relapses do not occur at random. Keeping a record of your additional activities (i.e. other than the basics you do every day) is also helpful because some exacerbations occur several days after the event. If you've kept a diary, it's easy to check if you did anything unusual several days ago. Admittedly, this doesn't always work during relapses, but with pacing, those should reduce. To save space, why not list medications at the top, then what you've eaten, with symptoms at the side. Use code, e.g. F or fatigue or if you can't stand the F word, T for tiredness, N for nausea, V for vertigo. OK for a good day.



Dr. Ho-Yen advocates something similar but also mentions including how you feel emotionally. It's up to you to determine which you prefer. In the beginning, add an assessment of stress levels. Stress saps your energy and can further undermine your immune system. If you can't avoid it, or it gets to you, talk things over with a friend or seek outside help. It needs treating just as the nausea, pain etc. do.

6. Move at a slower pace

Dr Ho-Yen advocates doing everything more slowly. If that works for you, fine. Sometimes walking more slowly helps extend one's energy

but I have no hard and fast rules. It's a question of experimenting and seeing what works. The basic rule is just not to over-exert or push yourself when your body lets you know that you are running out of stamina.

7. Increase activity when you are ready

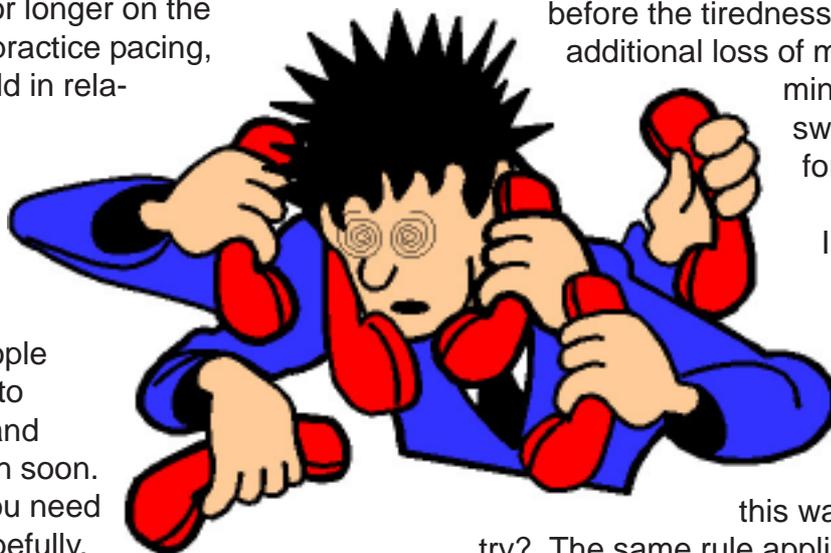
When should you increase your level of activity? Newer versions of pacing advise a gradual increase every few days. This assumes that the previous level did not lead to a marked exacerbation and that medically, you are stable. However my concept of pacing means responding to your symptoms so if you feel OK, there's no reason to stop. If you want to increase your activity levels, you are free to do so as long as you don't over-exert yourself in the process. It's similar, except that I don't advise people to make plans, or aim at targets and goals.

8. Pace telephone calls

I've known many patients who spend 30-40 minutes or longer on the phone. Please practice pacing, just as you would in relation to physical activity.

When you begin to flag or brain fog descends, end the call. Tell people that it was nice to speak to them and you'll be in touch soon. Or admit that you need to rest now. Hopefully, they'll understand that it's medical and not personal.

Other ideas: If you ring another patient, ask how they are and if he or she mentions being very tired or unwell, keep the call short or ask if it's OK to chat. Similarly, if you're talking and someone mentions time, why not take it as an opportunity to see if the other is still as energetic as you? Another sign of someone reaching or going beyond their limit is a longish pause. Don't ignore such cues.



A lot of the severely affected keep contact with friends by telephone. They depend on it. Hence it's an important issue. Perhaps when it comes to calls to friends with ME/PFVS, the motto should be 'little and often'?

9. Extend energy levels by 'switching'

Switching means changing activities to avoid tiring specific muscles. For instance, if you've been reading for a while, stop before your eye muscles get tired and do something which involves a different muscle group, e.g. walking, washing clothes, eating, talking. Do that for a while (stop before you reach your limit), and then switch again (you can even go back to reading).

Research has found that the muscles of patients with ME lose strength in the same way as healthy people during exercise but that unlike everyone else, they continue to lose strength for at least 24 hours afterwards. A Consultant who has been studying ME since 1955 wondered if stopping an activity before the tiredness set in might keep the additional loss of muscle strength to a minimum. He began switching, and it worked for him.

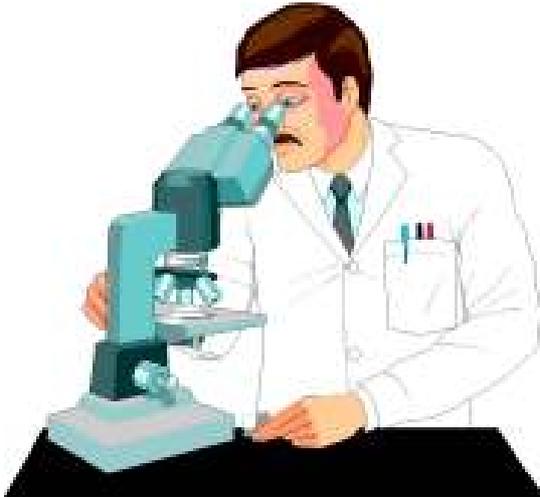
I know that it's not easy to stop activities, which you haven't finished but on the other hand, if you can extend your energy levels this way, why not give it a try? The same rule applies to mental exertion (i.e. switch before you start feeling tired).

10. Balance physical activity, mental activity & rest

Also, remember to balance physical and mental activities with rest (and that doesn't mean watching TV). If you're in a relapse, you may have to be strict i.e. physical activity - rest - mental activity - rest etc. However, as you improve, you should be able to do more and rest less without paying for it. See what and how much you can manage in a day using this new method. It takes a fair amount of self-discipline but what have you got to lose?

The science bit

It should be obvious that pacing is not a type of treatment or therapy. It is simply a way of managing energy. Ideally, it should be part of a programme, which also includes medical care, emotional support, dietary advice etc. Indeed, it can be combined with cognitive-behaviour therapy, counselling, in fact, everything except graded exercise. However, without medical advice and symptomatic treatment, any improvements are likely to be limited. (cf. Friedberg and Krupp 1994).



Regarding the theory: the reports of easy fatiguability are consistent with research by Paul et al. (1999). They found objective evidence of a loss of muscle strength, showing that this aspect of ME is not merely a result of (faulty) perception. Similarly, Jason et al. (1999) documented reductions in energy linked to exertion.

There are also studies by Lane and others who found metabolic abnormalities in patients with well-defined CFS (which includes many people with ME). The alternative to pacing, i.e. graded activity, assumes there is no physical abnormality causing the fatigue and certainly no disease. Any abnormalities are deemed to be the result of a lack of fitness (deconditioning) and hence can be safely ignored.

Pacing makes no such assumptions. It recognises the research linking ME with organic disease plus the studies showing that deconditioning is not an important determinant of CFS (e.g. Bazelmans et al. 2001, Sargent et al. 2002).

Controlled studies which included advice on conserving energy and pacing yourself include Friedberg and Krupp 1994 (who combined it with CBT) and Goudsmit 1996, who assessed a broad programme also including medical care, emotional support and advice on sleeping and avoiding stress. The first found that this combination was of limited benefit, except for those with depression. The second reported that about 80% of patients with post-infectious fatigue syndrome felt better as a result of this approach.

Finally, several large surveys have reported that the majority of patients find pacing helpful (e.g. CFIDS Chronicle, July/August 1999). I cannot be sure, but I suspect that these patients were using my basic approach, rather than the newer versions.

Pacing versus graded activity

As I've noted before, pacing does not rely on plans. Indeed, if you see references to plans, goals or targets, you are probably reading about some form of graded activity.

Graded activity or as it is sometimes known, graded exercise therapy (GET), is based on a theory. This theory assumes there is no ongoing disease process, but that symptoms after the acute phase are largely the result of a lack of fitness due to avoidance behaviour, plus stress, anxiety or depression. Hence it is considered safe to push yourself a little in order to reach goals.



Indeed, proponents of this approach believe that listening to your body is likely to perpetuate the illness,

as you need to increase your activity levels to improve your fitness. (No pain, no gain). Those advocating GET also refer to consistency in order to avoid the boom-bust cycle of overexertion and relapse.

(Pacing limits the number and severity of relapses so you don't get these cycles.)

In my view, GET is a good way to increase your fitness or to recover from a period of stress or depression. However, there is no evidence that it works for people with neurological or immunological symptoms, and indeed, there is no evidence that the theory on which it is based is applicable to the majority of patients with CFS. Thus from an evidence-based perspective, I cannot recommend it as a general approach for people with ME. On the other hand, if you're clearly recovering, gradually increasing your activity levels is unlikely to do you any harm.

Conclusion

Pacing, with or without switching will not help everyone with ME or CFS, and it almost certainly will not help on its own. It's not a form of therapy, just advice regarding energy management. If followed, this strategy will help to limit the number and severity of relapses, and avoid at least some of the complications of inactivity. It's an evidence-based approach which takes account of all the research, and which thousands of patients have found useful for many years. And above all, it doesn't make assumptions about the cause of the symptoms, so it is unlikely to cause harm.

Key references

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