Energy Management in ME/CFS

Striking the right balance between activity and rest is one of the most difficult aspects of coming to terms with ME/CFS.

On one hand is the need to take an appropriate amount of rest and relaxation, especially during the very early stages, as well as during periods of relapse or an exacerbation of symptoms.

On the other is a natural desire to want to increase physical and mental activity when you’re starting to feel that some improvement is, at last, being made.

Achieving the right balance also has to take into account the fact that exceeding your limitations by sometimes only a very small amount can easily cause an exacerbation of symptoms.

And, as most people with ME/CFS quickly discover, cramming too much in on a ‘good day’ often results in ‘just feeling awful’ the next – the result being an all too familiar vicious circle of over-activity followed by setbacks.

So how do you balance the two?

DETERMINE WHAT’S RIGHT FOR YOU

There are very few rigid rules when it comes to basic energy management in ME/CFS – the amount of activity and rest you need to take has to be largely based on your own individual circumstances. This means taking three important factors into consideration:

- What stage you are in the illness – acute, stabilising or transitional, or recovery.
- How severe your symptoms are – mild, moderate, or severe.
- To what extent your condition fluctuates on a day by day basis.

BASIC ENERGY MANAGEMENT

The guidance that follows is largely based on the principle of pacing – an approach to activity management that was found to be helpful by almost 90% of those who provided feedback to the 2002 Chief Medical Officer’s Report into ME/CFS.

You can find more information on pacing in section 4.4.2.3 of the CMO report and in the 1994 Task Force report.

A simple way of understanding how energy management works in practice is to compare your body’s energy supply to that of a rechargeable battery.

Drain the battery too quickly, and you’ll soon run out of available energy. But make use your energy in small, regular amounts, always allow time in between to ‘top up’ the supplies, and you’re far more likely to have some available when you need it again.

So one of the key components of this type of energy management is to stop your activities before you reach the point of fatigue or symptom exacerbation – an approach that is sometimes known as the 75% rule.

And don’t forget that energy management has to include mental and emotional activity as well as the purely physical!

ENERGY MANAGEMENT DURING THE VERY EARLY STAGES OF ME/CFS

For anyone who has been perfectly well, then falls ill with an infection, and from that point onwards ‘fails to recover’ with the classic symptoms of ME/CFS, anecdotal evidence strongly suggests that an adequate period of rest, probably including a period of bed rest, is very advisable.

If bed rest is taken at this stage, this should usually be combined with
either in a chair, or mobilising yourself about the house – because prolonged immobilisation in bed isn’t a good idea. Passive limb exercises should also be carried out during an initial period of bed rest.

Sadly, all too often we hear about people who have tried to exercise their way out of the very early stages of ME/CFS, or gone back too work or school far too soon.

Although there’s a desperate lack research into what may be the best approach to activity management during the very early stages, evidence from people with this illness indicates that an adequate period of rest is one way in which it may be possible to reduce severity later on.

**ONCE THE ACUTE STAGE IS OVER...**

Fortunately, only a small minority of people with ME/CFS make little or no recovery following a triggering infection.

For those who do, a cautious step-by-step approach to energy management is advised. The aim is to make small increases in physical and mental activity. It’s a process that has much in common with convalescence – something that has largely gone out fashion as a way of helping recovery from debilitating infections.

Any activity at this stage should be interwoven with regular periods of rest or relaxation. To relax properly means learning how to ‘switch off’ completely, both physically and mentally.

Learning how to breathe slowly and regularly can be an equally important part of a relaxation programme. Relaxation tapes and books are helpful here.

If you feel ready to undertake more complicated activities – preparing and cooking a meal for example – try to split the task into several small chunks of activity followed by roughly equal periods of rest. Many people find it helpful to switch between mental and physical activities as the day goes on.

During this phase of the illness you may still require periods of bed rest during the day. But try to ensure that daytime sleeping isn’t then interfering with your ability to have at least five or six hours of good solid sleep each night.

Any return to work, school, or domestic activities in the home, has to be carried out in a flexible and gradual manner. If an attempt to return to part-time employment or schooling isn’t successful, there’s no point in trying to push on regardless. This will only result in a relapse and it then becomes far more difficult to make any progress second time round.

Keeping a daily diary of your progress can be helpful at this stage. A diary can also pick out routines which are clearly helpful and others which are not.

**SIX MONTHS PLUS: STABILISATION, TRANSITION, AND RECOVERY FOR SOME**

Research studies into the long-term outcome of ME/CFS (ie what happens after six months of ill health) indicate that some people continue to make good progress and eventually return to normal or near normal levels of health.

If you’re experiencing a progressive degree of recovery, with very little in the way of relapses or exacerbations, then it’s usually quite safe to continue with gradually increasing your periods of mental and physical activity while reducing the amount of daytime rest and relaxation.

**A VARIABLE PATTERN OF RECOVERY**

The majority of people with ME/CFS reach a point where their condition, although improved, enters a more chronic phase. This usually involves a significant and continuing reduction in their ability to carry out physical and mental activities – a situation that also tends to fluctuate on a day-to-day and week-to-week basis.

So on ‘good days’ you may function at up to say 60% of what you would regard as normal. On ‘bad days’, this may slip right down to 20%. No matter how hard you try, it’s just not possible to break through the barrier – or ‘glass ceiling’ – which forms your upper limit.

At this point it’s sometimes helpful vto go right back and re-establish a baseline of physical and mental activity with which you feel entirely comfortable.

In practice, this means finding a level of activity that you can comfortably and consistently carry out on a regular basis – regardless of whether you are going through a ‘good patch’ or a ‘bad patch’.

In many cases this means accepting a slightly lower level of activity than you’ve become used to. For some, this might even mean a much greater reduction in the amount of day-to-day activity you normally carry out. From then on, the amount of activity should be very gradually increased, once again in small chunks which are interspersed with periods of rest and relaxation.

Remember the comparison with a battery – it’s far better to stop doing something while you are still feeling OK than to go on until you feel you have to stop.

Plans or goals have to be realistic, achievable, and sustainable. And you’ll have to accept that progress may turn out to be two steps up followed by one step down every so often.

**ASKING FOR PROFESSIONAL HELP**

Some people have found regular guidance and monitoring from an occupational therapist or physiotherapist who knows about ME/
CFS to be helpful. If no such service is available locally on the NHS, there are physiotherapists working in private practice who might be worth a try. You could also try the Chartered Society of Physiotherapists website: www.csp.org.uk

If you are having major problems with mental functioning, then a psychologist may be able to help you to plan your activities more appropriately.

**CHRONIC AND SEVERE ME/CFS**

If you belong to the severely affected group of people with ME/ CFS, any increase in physical or mental activity will have to be carried out in very small amounts, preferably with the help of a health professional who fully understands this illness.

In the case of physical activity, this will probably involve passive physiotherapy – something which again requires advice and guidance from an experienced OT or physiotherapist. Problems associated with more prolonged inactivity such as thinning of the bones (osteoporosis) may need to be addressed as well.

**COPING WITH A RELAPSE**

At the first sign of a relapse – which can be caused by an infection, trauma or surgery – it’s a good idea to reduce your activity levels as soon as possible.

If your symptoms are predominantly ‘toxic’ in nature (eg fever, sore throat, enlarged glands), a short period of bed rest is probably a sensible course of action. This should be followed by a period of convalescence during which there is a gradual return to previous levels of activity. However, it may take several weeks or months before you feel as though you can do what you’ve been used to doing before.

**WHAT SORT OF ACTIVITIES ARE HELPFUL?**

For many people with ME/CFS, the only real option with physical activity to start with is to gradually increase the amount of walking you carry out. Some gentle muscle stretching exercises before you set off can be helpful as well.

Having a swim in a warm pool, just once a week to start with, is another form of activity that could be introduced later if recovery is progressing well. With swimming, check to see if the water is heated up on certain days of the week. You may even be able to go to an NHS hydrotherapy pool – if there is one available at a local hospital. The buoyancy provided by warm water is sometimes helpful for easing pains in stiff muscles and joints.

Another gentle form of muscle-stretching activity worth considering is low-impact yoga.

Reintroducing short periods of mental activity can be done through just trying to read a chapter of a book in small chunks, doing some very limited work on a computer, or trying word or mathematical puzzles - perhaps even some basic Su Doku.

**WHAT SORT OF ACTIVITIES ARE HARMFUL?**

Any type of sudden or intense activity will almost certainly lead to an exacerbation of symptoms or a full scale relapse. So avoid!

Graded exercise regimes that involve a progressive and inflexible increase in physical activity, regardless of how the person is coping, are also likely very likely to cause a relapse.

A small number of clinical trials have demonstrated some benefit in some people with chronic fatigue syndromes, following the use of graded exercise programmes. However, patient feedback included to the Chief Medical Officer’s Report indicated that around 50% found that graded exercise treatment had made their condition ‘worse’.

It should also be noted that prescriptions for exercise must be given with just as much care as those for drugs. So doctors who prescribe exercise therapy must ensure that this is mutually agreed, properly supervised, and is appropriate for the stage and severity of someone’s illness.

With mental activity, anything that increases stress levels – eg having to meet deadlines or requiring intense concentration – isn’t going to be helpful. Not surprisingly, anything that causes emotional stress will not help your progress.

**FURTHER INFORMATION**

Our companion leaflet on pacing, produced for the ME Connect helpline service, is a useful source of additional information. Copies can be obtained from our head office – if it's not already included with this one.

The Chief Medical Officer’s report on ME/CFS is available as a free download from our website at https://tinyurl.com/hwey74o

A detailed review of rest and exercise can be found in Chapter 11 (pages 203 - 221) of my book Living with ME.

Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your own doctor.

The ME Association recommends that you always consult your own doctor or healthcare professional about any specific problems.

We also recommend that any of the medical information provided by The MEA in this leaflet is, where appropriate, shown to and discussed with your doctor.
Pacing for people with ME

Pacing is the balance we strike between activity and rest. For most people pacing makes the difference between feeling tired or fresh but – for people with M.E. – it can make the difference between feeling fair or desperately ill.

Activity can mean very different things. There is physical, emotional or mental activity and with M.E. each of these can affect the others.

You can gain control of the illness, and your life, by learning to manage your available energy. You will need to learn new skills and exercise strong willpower. Sometimes this is very difficult, especially when you are feeling awful, but you should see that slowly you are coping better and the symptoms are starting to resolve.

AIMS

You are aiming to gain stability in the way you feel. This stability shows that you have gained control over your activities and that you are not allowing yourself to get hopelessly overtired.

Every day you should be feeling the same, possibly only fair, but certainly not good one day and terrible the next, often described as “boom and bust”.

Once this control has been achieved, you can then start to increase your activities very slowly whilst maintaining the feeling of stability.

BASELINE

The first thing you have to do is to find your baseline of activity levels. This is often even lower than you think.

Keep dropping your activity level and increasing your resting until every day is the same and you feel you have control at last. This can take some time, with much trial and error, and the occasional disastrous mistake.

Keeping a daily activity diary for a week can show up where you might be making mistakes, but do not keep this going too long. It is better to learn by listening to your body and being really honest about what you can cope with.

ENERGY BANK

It is sometimes helpful to think of your energy like a bank account.

At the start of each day, you have a certain amount of energy to last you until the next morning. You need to be prudent and only “spend” this energy in small parcels so that by the end of the day you have just a little left. Remember that you are not allowed to go overdrawn without drastic consequences.

REVIEW YOUR PRIORITIES

- Do not feel guilty
- Remember you are ill; put yourself and your health first
- Is the activity needed at all?
- Can you put it off?
- Learn to say no
- Learn to ask for help
- Alter your way of doing things
- Include things purely for enjoyment
- Do not aim to finish the task in one go
**Showering**

Choose and lay out your clothes then have a rest.

Rest in a towelling robe after showering and you do not need to dry yourself.

**These principles should be applied to all your activities all the time.**

**Switching**

Once you are able to achieve a little more without any ill effects, you can then try switching to a different type of activity rather than having a rest.

You might do some work on the computer (mental activity) and then a small amount of ironing (physical activity) and then have a rest.

**Rest**

Resting is a skill to be learnt. You must give yourself permission to rest and not feel any guilt. Remember you are ill.

**There are different types of rest:**

Complete rest when there is no outside stimulation. Put on the answerphone and shut the door. Explain to others what you are doing.

Reading or watching the television.

Mini rests between chunks of an activity, such as ironing.

You may need to practise relaxation techniques with the help of tapes, or books.

It is possible to overdo the resting, particularly when you are fearful of doing too much and causing a relapse. Learn how to pace yourself and this anxiety will reduce.

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**Activity**

When doing any activity, whether it is physical, emotional or mental, you must remember that the fatigue it causes sometimes only appears after a delay.

Instead, you need to recognise the feeling of "doing too much" which is often not a feeling of tiredness. It can be that you feel stressed, anxious or that you lose concentration.

Do not fight the illness; stop the activity when your body tells you to.

You should try to stop an activity before you feel you are doing too much.

All activities need to be done in manageable chunks. Although frustrating, this means that eventually you will complete the task, although much later in the day than you would like.

*Here are some examples:*

**Preparation of a simple meal**

- Plan what needs doing, check the fridge, count out the vegetables. Rest.
- Prepare some of the vegetables and lay the table. Rest.
- Cook the vegetables (for reheating later), prepare the meat for grilling. Rest.
- Grill the meat, heat the vegetables. Enjoy your meal! Rest.
- Leave the table clearing and washing up until later.

**Ironing**

Organise the clothes so that easy things are alternated with shirts etc.

Iron half a shirt, then have a brief rest before ironing the other half.

Put the clothes away later.
**IMPROVING**

Once you have achieved a sustainable level of activity, you will feel that you have control and your confidence will grow. Only now should you start to increase these activity levels. You can increase the number of activities and the amount but of course only by tiny amounts.

Listen to your body and stop the activity before any fatigue sets in. You may have to resume the lower levels for a little while longer.

**PROBLEMS**

If you cannot get your symptoms under control, you may need to discuss them with your doctor in order to get further treatment. If they are allowed to continue, they may stop you pacing successfully.

Any new symptoms need to be reported to your doctor, as they may be unconnected to M.E. These may also stop you pacing successfully.

Always have a reserve of energy and never work up to your maximum. Any unexpected demands need to be counter-balanced by removing something from your plan for the day.

Do not forget that tiredness and stiffness are a normal reaction to hard work. Do not panic and assume you are having a relapse. Continue to pace as usual.

**RELAPSES**

Pacing is a skill to be learnt and there will be times when you misjudge your capacity. Do not blame yourself for making mistakes.

Be prepared to drop your activity levels, but do not go back to the beginning unless really necessary.

Reset your baseline.
Do not increase activity until you feel stable.
Learn from the experience.

**ENJOY YOUR LIFE!**

You need to accept that you are ill, but nevertheless you need some enjoyment.
Your plan for the day should contain some activities that are there only for you. They should be a priority and not added on the end of the list if you have spare capacity.

If you have a big event coming up, you will be anxious about whether you can cope and what effect this will have on you. Make a sensible and realistic plan and stick to it.

Explain to people about your limitations. They will understand and be helpful. Do not try to hide your problems.

Plan your travel and timetable well in advance, and be prepared to alter it if necessary. Find a suitable place where you can be restful and quiet. Have a rest before you feel tired.

If you overdo things, do not worry. You have already proved that you can gain control by pacing and you will succeed again.

**SUMMARY**

- You are ill. Make allowances for yourself. Do not feel guilty.
- Get an accurate baseline before trying to increase your activities.
- Break up any activity into manageable chunks.
- Switch to other types of activities or have a proper rest before you feel tired.
- Feel your confidence grow as you gain control of your life
- Enjoy yourself whenever you can.