



Setting The Pace

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What is Pacing?

Pacing is recognised by health care professionals as an effective treatment for CFS/ME, and is a technique which many people with CFS/ME find helpful. It allows those with the condition to manage it better, and improve their quality of life. Pacing involves achieving the correct balance between rest and activity, and establishing a daily routine which can be carried out on both good and bad days. It is suitable for people with mild, moderate or severe forms of the illness.

“Pacing helps me to set myself targets for the day, making sure that I’m not wearing myself out...I place myself with my tasks, carrying out activities, resting then doing another activity, but making sure that I give myself enough time to relax and to recharge afterwards so that the next day isn’t jeopardised.” Robert

Many people with CFS/ME fall into a pattern of **‘boom and bust’**. They do too much on good days resulting in a subsequent increase in symptoms, and then need a period of prolonged rest. Bad days are usually the result of doing too much, and if this pattern continues, many people with CFS/ME find that the amount they can do on a good day decreases and they are able to do less and less.

A pattern of ‘boom and bust’ does not promote recovery, and can lead to a worsening of symptoms. This can be demoralising and make it even harder to live with CFS/ME. Pacing aims to minimise this ‘peaking and troughing’.

“Some days I’d get this spurt of energy and I’d think “great”. I’d start doing things I didn’t normally have the energy to do, like cleaning the fridge out or emptying a cupboard but then I’d end up not being able to put the stuff back because I felt so ill.... I realised that I’d got to get my head round pacing my activities otherwise I was going to be like that all the time... just cleaning the fridge out could make my energy levels so low for many days afterwards that it wrecked my whole week... I thought there’s got to be a better way of doing things than this”. Angie

The Basics

Natural Rhythms

The body has its own natural rhythms. For example, we generally feel hungry, sleep, and go to the toilet at certain times. These rhythms dictate when we feel most alert and at our best. In some people with CFS/ME these rhythms are disturbed. Before pacing can be carried out effectively the body’s natural rhythms must be re-established. Sleep is particularly important.

Sleep

Sleep recharges mind and body. Many people with CFS/ME have problems with sleep. Restful sleep is an important part of the recovery process and sleep problems need to be tackled. The following suggestions may help

- Go to bed and get up at regular times
- Establish a bedtime routine. Try to relax and wind down by taking a bath or having a milky drink.
- Dim the lights in the evening e.g. in the lounge
- Don't use the computer or engage in any activities which are too stimulating in the evening e.g. watching horror films or listening to rock music.
- Avoid tea, coffee or cola drinks after midday. These are stimulants and will keep you awake.
- Avoid a heavy meal close to bedtime.
- If you have something on your mind which is making it difficult to sleep, write it on a piece of paper and deal with it in the morning.
- Ensure the bedroom is comfortable. Control noise, temperature and light.
- Medication can be useful. Talk to your Doctor about this.

Task

Do the following statements describe your bedroom?

There are blackout curtains

The duvet or covers are changed from winter to summer

There is no television or radio. These may stimulate your nervous system.

The bed is only used for sleep and sex

"I suffer from quite poor sleep patterns...I go to bed early; bedtime for me is anything from 7.30pm depending on how poorly I'm feeling...I try not to sleep too much during the day because I'm told its supposed to help me sleep at night if I don't but some days I just can't keep awake" Suzanne

Summary

- The body's natural rhythms need to be re-established before pacing can be carried out effectively.
- Adopt behaviour patterns and create an environment which aids sleep

Getting Started with Pacing

Understanding your current activity pattern

Before you begin to pace, you need to look back and reflect on your daily routine.

1. Keeping a Response Diary

The first step is to keep a daily response diary in which you record everything you do and your fatigue levels. This is very important as it will allow you to gain a better understanding of how much you are doing and which activities are more or less demanding. It should also enable you to see when you are doing too much and whether there are activities which make your symptoms worse. You should be aware that sometimes the effects of doing too much are delayed and may not be felt until the following day, or even several days later.

Task

Jot down in an ordinary diary the activities you do, for how long you do them, your fatigue levels and any comments you wish to make.

You should also record your rest periods. Score your fatigue levels from 0 to 10 where 0 indicates no fatigue and 10 is total exhaustion ie. you are unable to do anything else and have to go and lie down. Keep this diary for 2 weeks.

2. Grading your activities into high, medium or low energy demand

Individual activities require varying amounts of energy. Different people find different activities more or less demanding. For example, for someone with severe CFS/ME having a wash might be a high energy demand activity. For a person with a mild form of the condition a high energy demand activity might be going to work. Everyone with CFS/ME is individual. It is also important to recognise that mental tasks can be just as tiring as physical ones. Talking to a friend on the phone, reading, or concentrating on a film may be just as tiring as going for a walk. Emotional situations can also be very draining and you should be aware of this when planning your day.

Task

Look at your diary and fatigue levels and make a list of activities which you consider to be high, medium and low energy demand activities for you.

3. Incorporating rest into your daily routine

You may notice from your diary that you only rest when you are exhausted. If you are taking rest regularly, well done! In order to pace successfully it is necessary to follow periods of activity with periods of rest. Rest for people with CFS/ME should involve not only relaxing the body, but also calming the mind. Watching television or reading, which are regarded by most people as relaxation, should be viewed as activities for someone with CFS/ME, especially for those with severe forms of the condition. Rest does not, however, mean sleep.

How can I rest properly?

- Practice formal relaxation techniques such as meditation or visualisation.
- Listen to gentle music
- Sit quietly with your eyes closed for 5 minutes
- Rest in a darkened room to reduce stimulation
- Sit or lie in a comfortable, well-supported position. However, do not stay in one position for a long period of time.

“A technique I use to relax is the ‘square box’ technique which combines visualising a square in your head and using the sides as a breathing exercise. With the square in your mind, visualise breathing in for a count of three across the top, then hold your breath for three counts, then exhale for three counts, then rest... it helps your brain calm down and you to calm down yourself. Robert

“If I’ve been worried about something... I imagine my problem is being put inside a brightly coloured balloon and I let the balloon float above my head. I attach to the bottom of the balloon a brightly coloured ribbon so that I know if I need to think about the problem I can pull the balloon down towards me, think about it and deal with it at the time, but so that I don’t dwell on things I let the balloon float free and think about it when I need to” Suzanne

Task

Decide how many rest periods you need and when you will have these.

Decide how you are going to rest effectively. Jot down what approaches you are going to use.

Summary

Collect information to help you understand your current activity pattern. Do this by keeping a response diary and grading your activities into high, medium and low energy demand.

Build rest into your daily routine. A period of activity should always be followed by a period of rest.

Setting a Baseline

Your baseline is a comfortable level of activity that can be managed on both good and bad days without causing an increase in symptoms. It is important to remember that your baseline is not going to be where you were before you were ill. It is also helpful to compare

yourself to other people with CFS/ME. Everyone is individual and CFS/ME affects people in different ways.

To calculate a baseline

Record how long you carry out a specific activity for each day of the week, e.g. watching TV

Work out an average length of time for each activity per day, e.g. you may watch TV for an average of 30 minutes each day.

Reduce this figure by a third. This is your baseline.

To calculate Mary's Baselines

Mary	Housework (moderate)	Walking	Watching TV
Monday	None	10 mins	90 mins
Tuesday	60 mins	30 mins	30 mins, 90 mins
Wednesday	None	None	None
Thursday	30 mins	15 mins	60 mins, 120 mins
Friday	None	30 mins	60 mins
Saturday	15 mins	20 mins	105 mins
Sunday	None	None	None

To calculate Mary's baseline for housework (moderate housework = ironing, tidying up etc):

Total amount of moderate housework done each week = 105 minutes

Average amount done per day = $105/7 = 15$ minutes

Reduce this total by approximately a third = 10 minutes

Mary's Baselines

Housework (moderate) 10 minutes per day

Walking 10 minutes per day

Watching TV 55 minutes per day

Task

Make a list of the main activities you carry out each week. Work out a baseline for each of these activities. Use the chart to help you.

Summary

Work out your baseline. This will be used as the basis for creating a weekly programme of activities.

Activity Chart

Activity	Tick if this appears on your diary sheet	Total hours per week	Average time per day	Baseline (average time minus a third)
Washing-body wash				
Shower/bath				
Wash hair				
Dry hair				
Sitting in bed				
Sitting in a chair				
Standing to do tasks				
Walking				
Climbing stairs				
Meal and drink preparation				
Food shopping				
Reading				
Talking on telephone or face to face				
TV				
Computer				
Listening to music				
Driving				
Gardening				
Housework (light)				
Housework (heavy)				
Working/studying				
Looking after children				
Socialising				

Exercise				
Other				

Setting Priorities

Prioritisation is about deciding what to include of current demands on your energy and what to leave out. It is not about increasing activity.

Task

Divide your activities into:

Jobs that must be done e.g. washing, dressing.

Jobs that someone else can do.

Jobs that you enjoy. Build pleasure or treats into your day. Even if you are severely affected, it is still possible to build some enjoyment into the day. For example, pleasure can be gained from something as small as smelling flowers in your bedroom, or the sense of peace and tranquillity in a quiet house. As your energy levels increase the activities that give you pleasure will change, but if possible they should always be part of your daily routine. Building pleasure into your day will also help lift your mood, and improve your self-esteem.

Jobs that can be eliminated.

This should help you to create a weekly plan

At the beginning I had to prioritise things...so if I had the choice between going to the toilet and doing 10 minutes reading, of course I would save my energy for going to the toilet...the most important thing for me was being able to do self-care...being able to wash myself...feed myself and go to the toilet on my own; these were my priorities at the beginning...and at the beginning all my pacing and my immediate, medium and long term goals were to do with these three things. Jolanta

"Because I don't have the energy to do lots of things, I'll put off things I don't like doing like the ironing. I'll prioritise, if it's a nice day then I'll be in the garden and it doesn't matter what the house is like...but I will prioritise what I think is important to me at the particular time and everything else is just left" Jane

Summary

Prioritisation will help you decide what to include in your weekly plan. Always include activities which give you pleasure.

Planning a Programme of Activities

In order to keep on an even keel and avoid a 'boom and bust' pattern it is necessary to plan ahead. Now you know which activities are most demanding, you can plan a whole week. If possible try to do the same amount each day. Activities such as housework may need to be broken down into smaller parts and spread over the week.

Breaking tasks down

Break tasks down into small chunks with periods of rest in between. This can apply to high or low energy tasks. Washing and dressing could be broken down into stages e.g.

- Get clothes out
- Rest
- Walk to the bathroom
- Sit on a stool at the sink
- Rest
- Wash
- Sit in a towelling robe and rest
- Walk back to the bedroom
- Rest
- Dress in clothes which are easy to put on
- Rest

More energetic activities can also be broken down to make them easier to manage.

"When I needed to decorate the hall I allowed myself over a week to do the task and I'd break it up into blocks. One day I would rub it down and fill any cracks, then have a rest and try to get my energy back for the next day. I would undercoat it the next day, then have a rest...and then finish off and gloss it" Robert

Task

Create a weekly programme of rest/activities that is tailored to your needs. Here are some additional guidelines to help you:

- You should get up and go to bed at the same time each day
- Include a 30 minute wind down period before bed
- Interweave periods of rest and activity
- Include as many rest periods as you need during the day
- To begin with stick to low and medium demand activities and avoid high demand activities together
- Try to alternate physical and mental activities to achieve a balance throughout the day

Please note that when specific activities are fitted into an activity period they do not necessarily have to fill the whole of the period .e.g Mary's baseline for walking is 10 minutes per day, it will not fill the 30 minute activity period between 10.30am and 11am. She should therefore sit down for the remaining 20 minutes.

“At the beginning you have to be very strict with yourself..the programme is the Bible for you. If you have to sit for 2 minutes, then you sit for 2 minutes and no longer, when you increase you increase by 1 minute and no longer. When you are supposed to be sitting and that’s in your programme, that’s what you do and when you are supposed to walk, that’s what you do...but once I got to the stage that I can sit up for 2 hours, 3 times a week and walk for 30 or 40 minutes, I very often swap activities. For example in the evening when I sit and watch TV or listen to the radio, very often during that time I will go out into the garden and swap activities...I can swap activities now and I don’t have to pay for it” Jolanta

“I have a rest/activity plan all through the day. I have my shower, then I’ll have a rest and then I’ll have lunch, then I’ll have a rest. Then I’ll do something pleasurable then have another little rest and then its dinner time...In the evening I’m resting anyway and by 10 I’m ready for bed” Angie

Examples of Activities with and without pacing

The following examples illustrate the benefits of pacing and planning your activities.

Wedding scenario without pacing

- You are invited to a wedding and reception
- You feel obliged to attend
- You get up very early to make the three hour drive
- You are very tired by the time you get to the church
- You feel increasingly fatigued through the ceremony
- You feel too ill to attend the reception
- This results in feelings of guilt
- You hear friends making comments about you leaving
- You feel exhausted and upset
- You are in bed for three days

Wedding scenario using pacing

- Decided just to go to the reception
- Travelled the day before and stayed in a hotel
- Had a relaxed morning
- Decided to go for two hours
- Stuck to it
- Stayed at hotel for the night
- Partner drove back
- Felt rested and relaxed

Gardening without pacing

- Wake up to a sunny day feeling good
- Decide to mow the lawn
- Notice that the weeding needs doing and the flower beds are dry
- Your body is saying STOP but you force yourself to go ON
- Unable to do anything for the next two days

Gardening using pacing skills

- Wake up to a sunny day feeling good
- Set yourself a target of mowing the back lawn
- Rest 2-3 hours
- If still feeling good carry out a less strenuous job in the garden such as watering the flower beds □ Rest

“Music’s really important to me so I really enjoy going to concerts. When a concert’s a bit further away from me I try to make it as easy as possible..If I’m going to drive over there I’ll try and get a hotel or a Travelodge...so we can have a rest before we go to the concert. We skip the support act, it conserves energy and means that I can enjoy the main act. Just lately I’ve been able to stand up for concerts, I still find it tiring and suffer for it a few days afterwards. I used to just sit down for concerts, but when I do stand, I try to find somewhere where I can lean on a wall so that I’ve got a bit of support...Sometimes I’ve had to leave the concert if I’ve been too ill...if I’m going to the concert at night, I’ll usually have a really easy day and sometimes I don’t get dressed until quite late in the day...i just rest until I’m actually going and then I’ll spend all my energy there” Molly

Summary

Create a weekly programme of rest/activities that is tailored to your needs
You may need to break tasks into smaller chunks and spread them across the day or week

Increasing Activity

Once you are comfortable with your daily routine and have established a baseline which you can maintain, you can begin to slowly start increasing your activity. Increase energy demand in tiny steps by adding a few minutes to an activity, or for those who are less severely affected, add another small, low-grade activity to your routine. As long as your symptoms do not worsen you can continue to gradually increase activity. Increasing activity is about small, short-term goals. Larger, long-term goals will be discussed in the section 'Continuing to live with CFS/ME.

"I couldn't feed myself, I couldn't wash myself, I was totally bedridden...they started first pacing me by sitting me up at first once a day for 1 minute, then after I was alright with that for a couple of weeks, twice a day for 1 minute, then 3 times for 1 minute. After I was able to sit 3 times a day for 1 minute they started to increase my sitting times by just 1 minute, not all of them at the same time, just 1 by 1, minute by minute..." Jolanta

Summary

Once you are comfortable with your weekly routine and can maintain your baseline, try and very slowly increase your activities

Relapses

Sometimes your symptoms will worsen; this is called a relapse. This can be a warning sign and indicate that you are doing too much. A relapse may also occur for other reasons, such as illness or stress. Many people with CFS/ME experience relapses. Usually they are shortlived and it should be possible to slowly return to previous levels of activity.

Top tips for managing a relapse

- Reduce your activity to a more manageable level
- Include more rest periods during the day
- Slowly increase to previous levels of activity

Listening to your body

It is important to listen to your body; you know best how you feel and you should always be in control of your own activity programme. Always stop well before your symptoms become too marked. It is important to be consistent, do the same amount of activity each day and be able to rest and recover after each activity rather than pushing yourself too hard.

Task

Make a list of 'slowdown' signals—symptoms you experience when you are doing too much. These are a warning sign and require an action plan.

Examples of possible 'slowdown signals'

Increased fatigue
Increased pain
More tearful than usual

Possible action plan

Stop doing housework for a couple of days
Speak to your GP
Ask for help from your family
Increase your rest periods
Relieve stress

"Before I became ill I was very very impatient...in those first few years of CFS/ME I had to increase things minute by minute and not rush things. Every time I tried to rush I had a setback" Jolanta

"When I first got ill I wasn't really sure how to manage my illness...in the last few years I've learnt to pace myself and listen to my body and only do things when I think I can. I used to do things because I didn't want to let people down...now I try to just listen to my body and do things when I feel able to" Molly

Summary

Be aware of relapses and adjust your activity levels accordingly. Always listen to your body and stop well before your symptoms become too marked.

Family and Relationships

Having a condition such as CFS/ME will affect those around you and your relationship with them. Your closest family will probably be aware of your condition but you will need to decide who else you want to tell and what information you want to give them. Those around you will be affected by your condition in a variety of ways and this may determine what you tell them. Some people such as a partner or carer may be affected every moment of the day. Others, such as distant relatives may only be affected occasionally. You may want to give different information to different people. Children also need to be considered and will need to be given information in a way which is tailored to their age and understanding. They may have questions such as "why is Mummy spending so much time in bed?" or "will I catch it?" and these questions need to be answered.

Your friends and family may feel a variety of emotions as a result of your illness. They may be anxious about what is wrong with you, or those closest to you may feel trapped or resentful. Many people don't know anything about CFS/ME and may find it difficult to understand. Their feelings towards you may alter. Think back to how you felt about people with CFS/ME before you had the condition and before you knew much about it. This will enable you to get an idea of how others might view you.

It is important to feel confident to explain CFS/ME to others and help them understand how you feel. Some relationships may need to be worked on. You may no longer be able to socialise and therefore need to find new ways of keeping in touch with friends. You may have to explain to your mother why you can no longer have long chats on the phone. Perhaps you need to make certain changes at work, for example by changing your working hours. This will require the support of your employer and the understanding of work colleagues. If the people around you understand your condition they will be more sympathetic and this will influence how they see you and what they expect of you. It is, therefore, very important that you explain your condition effectively.

Task

Think about who is affected by your CFS/ME and who you want to tell about your condition. Decide what information you want to give to those around you and how you can explain things to them most effectively.

“At the beginning visitors were a big thing because it was a huge drain on my energy. It cost me more in terms of energy having visitors than walking or sitting up...I had to limit visitors to twice a week for 10 minutes each, then increased it to half an hour. Now I can have visitors whenever I like, usually for about one hour but occasionally I can go out for a meal with friends. Jolanta

Summary

You need to consider your relationships with friends and family and those around you. Decide who you wish to tell about your condition and how best to explain it to them. You may need to give different information to different people.

Tips for Saving Energy

There are all sorts of ways to conserve energy. You may need to change the way you carry out certain tasks in order to save energy and make them more manageable. For example, you may need to prepare vegetables sitting down rather than standing up

Task

- Think about the way you carry out certain tasks using the tick chart provided.
- Consider your posture, the layout of your house, the equipment you use and whether any of these can be modified to save energy.

- Make the necessary adjustments
- Always remember to listen to your body and don't rush tasks

SIMPLIFY ACTIVITY	Tick if you do this
Select foods requiring minimal preparation time and effort	
Prepare part of the meal ahead of time to save your energy	
Cook larger quantities and freeze individual portions	
Leave washing up to drain rather than having to dry everything	
Soak dirty utensils and pans in the washing bowl so cleaning is easier	
Spread tasks over a period of time e.g. dust one day, Hoover the next	
Wash smaller loads of washing regularly, rather than doing several large loads in one day	
Try to buy clothes that are easy to wash and require little ironing	
Make one side of the bed completely, then do the other side to minimise the walking needed	
Shop when the store is quiet and ask an assistant to pack your shopping	
Use mail order or internet shopping when possible	

POSTURE	Tick is you do this
Sit down to prepare meals, iron, dress, etc.	
When hanging out washing place the basket of clothes on a chair so it is easier to reach	
Hang washing at shoulder height	
Use a trolley to transport heavy items so you haven't got to bend	

Check the layout of your work station if you work in an office. Make sure files etc are within easy reach	
Check you have good seating at work. Check the desk and chair heights and the back support	
LAYOUT OF HOUSE/ENVIRONMENT	Tick if you do this
Buy duplicate equipment for upstairs and downstairs e.g. kettle	
Keep all frequently used items in areas where they are in easy reach to prevent bending and stretching	
Go shopping in the same place so you know where products are located and it takes less energy to find them	
Check the citing of your work station if you work in an office so you avoid having to walk long distances within your workplace to do simple tasks	
Reduce the number of times you walk up and down the stairs	
EQUIPMENT	Tick if you do this
Uses electrical equipment e.g. food processors, electric toothbrush	
Use a microwave oven to reduce cooking time and cleaning up time	
Try adaptive equipment to minimise effort e.g. long handled tools	
Use fitted sheets and continental quilts to minimise effort	
Use a small trolley when shopping	
Use a towelling robe to dry after a bath or shower	
Use new technology such as video conferencing, e-mail etc to reduce the energy demands of your job	
Use a hands-free phone for long phone conversation	

Energy Saving Ideas

"I have a downstairs bathroom with an airing cupboard which contains my clothes, underwear, socks, towels etc so that once I've had my shower in the morning I haven't got to go back upstairs to get dressed. I also keep down there make-up, toiletries and my hairdryer so I've got everything at hand. I can dry my hair in the lounge and I don't have to go back up to the bedroom" Jane

Summary

There are many ways to save energy

Continuing to Live with CFS/ME

Longer-term targets

In the section on increasing activity, small, short-term goals were discussed. Once you have more control over your CFS/ME you can begin to aim at more ambitious targets. Setting targets is about increasing how much you do in specific areas but avoiding a previous boom and bust pattern. Choose one target at a time and break it down into manageable chunks as was discussed in the section 'Planning a programme of Activities'. Activities that may have been restricted by fatigue and you may want to work on could include:

- Social life - refusing invitations to visit friends
- Travelling - in cars, trains and buses
- Housework
- Walking a distance
- Being involved with the family/children
- Shopping
- Hobbies

A target will be personal to you

Simple Target Plan

Target: Mary want to be able to walk to the village shop once a day. It is a 15 minute walk from her house. To achieve this Mary needs to be able to walk for 30 minutes each day. At the moment Mary is walking for 15 minutes each day.

Plan: Mary needs to increase her walking by a small amount e.g. 1 or 2 minutes each week (for someone who is severely affected, this may be each month). To achieve this she can either walk some of the distance to the shop or elsewhere.

When Mary can walk for 30 minutes she should walk to the shop, buy something and come back. She should go at a quieter time at first to avoid having to stop and talk to people. She could also take someone with her.

Slowdown signals

Increased fatigue

Increased pain or aching in arms, legs and back

Feeling generally more unwell

Task

Decide what activity you want to improve

Set a realistic target and timescale

Review your target regularly - you may be achieving it faster or slower than anticipated

Be aware of any 'slowdown' signals and refer back to the section on 'Relapses' and 'Listening to your body'

Thinking Differently

To be able to pace effectively may require a change in outlook. You need to accept that you are living with a long term condition and now need to measure yourself against a different standard. You need to consider whether you are fulfilling all your personal obligations without making your CFS/ME worse.

Here are some common pitfalls

You feel dissatisfied with yourself, which can prompt you to do too much and make your fatigue worse rather than better

You may worry about how other people view your condition

You spend all your available energy doing things that are expected of you and none doing things that you enjoy

You push yourself too hard and try to achieve the same as you did before you became ill because your expectations of yourself have not altered

You may need to develop new skills to enable you to pace more effectively, You may need to

Ask people to assist you, or to do things for you

Say 'no' to people who expect too much of you

Become relaxed and discharge tension without being physically active.

"I do certainly ask other people for help at work if I'm struggling with something and they're very good. They understand that I get tired and we will share jobs..I'm not afraid to ask, although I do feel I need to prove myself a bit and take on jobs rather than saying I can't do that because I'm tired, as it feels like I am trying to get out of things. I'm aware that I sometimes do too much" Justin

Summary

Once you have more control over your CFS/ME you can begin to set yourself goals for the future.

In order to pace effectively you may also need to think differently and develop new skills.