Graded Exercise Therapy

A self-help guide for those with chronic fatigue syndrome/myalgic encephalomyelitis
Warning
Graded exercise therapy is a way of helping yourself cope with chronic fatigue syndrome or myalgic encephalomyelitis. Anyone wishing to undertake such therapy should first discuss it with their GP or hospital specialist and continue to consult them while undertaking the programme.

For further information, or to download a copy of this booklet, visit http://www.bartscfsme.org
What is graded exercise therapy (GET)?

This booklet is about the use of regular exercise and physical activity to help you feel less tired, improve your physical fitness, and reduce difficulties you have in your day-to-day living. The aim is to help you overcome limitations caused by the symptoms of chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME). Graded exercise therapy is the use of regular physical activity, starting with just a little and increasing the amount over time. We shall refer to graded exercise therapy as GET throughout this booklet.

A GET programme will help you gradually improve your ability to undertake some of the physical activities that you have been unable to do since becoming unwell.

It could therefore also be called a graded activity programme. Later on your GET schedule will include a regular exercise such as walking. Thus your routine will usually combine increased physical activity and regular exercise and we use both terms interchangeably when discussing establishing a GET programme.

Your exercise starting point or baseline will be your own current level of ability. You will then work towards physical goals and objectives that you have set yourself. For example, if your initial goal is to manage your home or garden better, you can develop a GET programme to help you achieve this by improving your overall strength, physical fitness and flexibility.
Will GET do me harm?

You may be worried that any increase in exercise or physical activity could make your condition worse. Be reassured - research has shown that a guided, gradual exercise programme can help people who suffer from CFS/ME without causing ill effects.

However, a self-help guide such as this has not been officially tested so it is important that you check first with your GP or hospital specialist that a GET schedule is suitable for you. You should also continue to consult them regularly while undertaking your GET programme.

Previous experience with exercise

In the past you may have been unable to improve your symptoms using an exercise programme, or you might have felt that exercise aggravated some of your symptoms.

There may be a number of reasons why exercise did not work for you before. You may have started at too high a level of physical exercise, or increased the amount you did too quickly. You may have used an exercise that was too challenging for you now such as jogging, which you could do perfectly well before you became ill with CFS/ME.

Adding exercise before you stabilised your daily routine, and while you were not getting enough good quality sleep or were stressed, could also have led to disappointment. The GET programme is specifically designed to reduce the likelihood of you having problems such as these.
Evidence for the benefits of GET

The 2007 National Institute for Clinical Excellence (NICE) guidelines for the management of CFS/ME recommend GET as one of the most effective therapies for CFS/ME. Regular physical activity is known to have considerable benefits: it improves the efficiency of the heart, lungs and circulation and generally helps the body to deal better with the demands of daily life. It can also help with losing weight and lead to an improvement in your:

- Strength, making daily tasks easier
- Endurance, e.g. you can walk further
- Flexibility, allowing joints to move more easily
- Balance
- Ability to fight infections
- Sleep quality
- Concentration
- Well-being and mood
- Confidence, self-esteem and social activity
The theory behind GET

Deconditioning

After a period of illness most people find that they take some time to recover. During this recovery period we tend to avoid physical activity and rest more than usual. When we do less each day our body loses fitness and strength in a physical process called deconditioning. The result of deconditioning is that we become physically tired much sooner.

Prolonged inactivity can also affect our sleep, hormonal rhythms, immune system and mood, making it more difficult to cope with day to day activities. The inability to function as before leads to frustration and an eventual lack of motivation for any physical activity. This starts a vicious cycle of avoiding activity and increased fatigue which then results in further deconditioning. The aim of GET is to break this cycle.

Boom and bust

CFS/ME can result in an erratic pattern of rest and activity, often called boom and bust. For example, on some days you may feel reasonably well and rush about doing a lot (the boom time). The next day you may feel tired and overcome by CFS/ME symptoms, or even unable to function (the bust time). This pattern may be better known to you as relapsing, crashing or having a setback. By following this boom-bust pattern the body does not have a chance to recover.

Before any new physical activity is started in the GET programme it is important to limit any boom-bust pattern. It is essential to stabilise your daily routine by spreading physical activity and rest evenly throughout the week. By continuing to boom and bust you may struggle to add any new exercise or activity and fail to progress as much as you would like as a result.
Physical symptoms of illness

- Decreased physical activity and more rest
- And/or boom and bust pattern

Physical deconditioning

Physical tiredness which could lead to:
- Increased fatigue
- Sleeping difficulties
- Hormonal imbalance
- Changes in mood
- Reduced immunity

Frustration and eventual lack of motivation
Reconditioning

Research shows that fitness and strength can be increased by gently re-introducing regular physical activity at a low level and gradually building this up over time - in other words using a GET programme. You will also start to feel better and sleep better as your general health improves.

Reconditioning the body in this way can break the vicious cycle of avoiding activity, deconditioning and a boom-bust pattern.
The GET programme: six steps to follow

**step 1**
Stabilise your routine

**step 2**
Start doing regular stretches

**step 3**
Decide on a goal and choose your exercise/physical activity

**step 4**
Set your exercise/physical activity baseline

**step 5**
Increase the duration of your exercise/physical activity

**step 6**
Increase the intensity of your exercise/physical activity
It is important to stabilise your daily routine: you need to work out a consistent schedule that spreads your activities over a week and throughout each day to avoid a boom/bust pattern. You should aim to do a similar amount of physical activity each day. You should also try to get up at the same time, eat meals at regular intervals and go to bed at the same hour every evening. Research has shown that a regular sleep pattern helps improve the quality and effectiveness of sleep.

On page 10 Julie’s boom-bust diary illustrates the type of pattern you want to avoid. The colours shown in the key below the chart represent Julie’s perception of the physical exertion needed for each task. The diary shows her busy working week with an irregular sleeping pattern, long working hours, overactivity early in the week with walks to and from work, erratic meal times and little time for resting.

As a consequence, Julie arrives at work later each day as she becomes more tired during the week. She is unable to do much at the weekend and has to cut short an evening out with friends on Saturday.

To start stabilising your routine you need to work out your current schedule by filling in your own activity diary for one week. Using Julie’s diary as a guide, include the times that you sleep and rest, and everything that you do graded into low, medium and high activities as shown. Make a note of how long a task takes if it is less than an hour; you could do this by noting the time beside the activity. Completing your diary for a week should help you to identify patterns in your daily routine. Use this information to modify your activities so you can balance high, moderate and low activity level tasks to reduce the risk of continuing, or entering, a deconditioning cycle.
Stablising your routine may take a week or longer.

Julie’s stablised routine is shown on page 11. As you can see, her daily tasks are now better balanced. Even though she appears to be less active during the weekdays than she was before, she is actually able to do more at the weekend. When you stabilise your daily routine you may well find you are less active than you were previously. Do not worry, you will be able to build up the amount that you can do each week as you follow your GET programme.
## Julie’s boom-bust diary

<table>
<thead>
<tr>
<th>Time</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
<th>Sunday</th>
</tr>
</thead>
<tbody>
<tr>
<td>7am</td>
<td>Wake, shower</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
</tr>
<tr>
<td>8am</td>
<td>Walk to work</td>
<td>Wake, shower</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
</tr>
<tr>
<td>9am</td>
<td>Work</td>
<td>Walk to work</td>
<td>Wake, shower</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
</tr>
<tr>
<td>10am</td>
<td>Work</td>
<td>Work</td>
<td>Bus to work</td>
<td>Wake, shower, breakfast</td>
<td>Sleep</td>
<td>Sleep</td>
<td></td>
</tr>
<tr>
<td>11am</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Bus to work</td>
<td>Bus to work</td>
<td>Wake up</td>
<td>Wake up</td>
</tr>
<tr>
<td>12 noon</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Lie in bed</td>
<td>Lie in bed</td>
</tr>
<tr>
<td>1pm</td>
<td>Work</td>
<td>Lunch</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Lunch</td>
<td>Lunch</td>
</tr>
<tr>
<td>2pm</td>
<td>Lunch</td>
<td>Work</td>
<td>Lunch</td>
<td>Lunch</td>
<td>Work</td>
<td>Watch TV</td>
<td>Sleep</td>
</tr>
<tr>
<td>3pm</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Watch TV</td>
<td>Watch TV</td>
</tr>
<tr>
<td>4pm</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Sleep</td>
<td>Watch TV</td>
</tr>
<tr>
<td>5pm</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Sleep</td>
<td>Watch TV</td>
</tr>
<tr>
<td>6pm</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Shopping</td>
<td>Shopping</td>
<td>Bus home</td>
<td>Cook/eat</td>
</tr>
<tr>
<td>7pm</td>
<td>Walk home</td>
<td>Walk home</td>
<td>Walk home</td>
<td>Out after work</td>
<td>Cook/eat</td>
<td>Out with friends</td>
<td>Cook/eat</td>
</tr>
<tr>
<td>8pm</td>
<td>Cook/eat</td>
<td>Study</td>
<td>Out</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Out with friends</td>
<td>Watch TV</td>
</tr>
<tr>
<td>9pm</td>
<td>Study</td>
<td>Yoga class</td>
<td>Cook/eat</td>
<td>Out</td>
<td>Sleep</td>
<td>Taxi home</td>
<td>Sleep</td>
</tr>
<tr>
<td>10pm</td>
<td>Watch TV</td>
<td>Read</td>
<td>Study</td>
<td>Out</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
</tr>
<tr>
<td>11pm</td>
<td>Read</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Bus home</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
</tr>
<tr>
<td>12am</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
</tr>
</tbody>
</table>

- **Blue**: high level physical activity/exercise
- **Light blue**: low level activity
- **Light green**: moderate activity/exercise
- **White**: rest/sleep
# Julie’s stabilised diary

<table>
<thead>
<tr>
<th>Time</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
<th>Sunday</th>
</tr>
</thead>
<tbody>
<tr>
<td>7am</td>
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<td>Sleep</td>
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</tr>
<tr>
<td></td>
<td>breakfast</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>8am</td>
<td>Watch TV</td>
<td>Listen to radio</td>
<td>Listen to radio</td>
<td>Listen to radio</td>
<td>Watch TV</td>
<td>Wake, shower,</td>
<td>Wake, shower,</td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>breakfast</td>
<td>breakfast</td>
</tr>
<tr>
<td>9am</td>
<td>Walk to work</td>
<td>Bus to work</td>
<td>Bus to work</td>
<td>Walk to work</td>
<td>Walk to work</td>
<td>Housework</td>
<td>Study</td>
</tr>
<tr>
<td>10am</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td></td>
<td>Study</td>
</tr>
<tr>
<td>11am</td>
<td>Work and rest*</td>
<td>Work and rest*</td>
<td>Work and rest*</td>
<td>Work and rest*</td>
<td>Work and rest*</td>
<td>Read</td>
<td>Read</td>
</tr>
<tr>
<td>12 noon</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Watch TV</td>
<td>Walk with friends</td>
</tr>
<tr>
<td>1pm</td>
<td>Lunch and rest*</td>
<td>Lunch and rest*</td>
<td>Lunch and rest*</td>
<td>Lunch and rest*</td>
<td>Lunch and rest*</td>
<td>Watch TV</td>
<td>Lunch out</td>
</tr>
<tr>
<td>2pm</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Lunch</td>
<td>Lunch out</td>
</tr>
<tr>
<td>3pm</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Rest</td>
<td>Rest</td>
</tr>
<tr>
<td>4pm</td>
<td>Work and rest*</td>
<td>Work and rest*</td>
<td>Work and rest*</td>
<td>Work and rest*</td>
<td>Work and rest*</td>
<td>Shopping</td>
<td>Housework</td>
</tr>
<tr>
<td>5pm</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Work</td>
<td>Bus home</td>
<td>Watch TV</td>
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<tr>
<td>6pm</td>
<td>Shopping</td>
<td>Bus home</td>
<td>Walk home</td>
<td>Out after work</td>
<td>Bus home</td>
<td>Watch TV</td>
<td>Watch TV</td>
</tr>
<tr>
<td>7pm</td>
<td>Bus home</td>
<td>Cook/eat</td>
<td>Watch TV</td>
<td>Out</td>
<td>Cook/eat</td>
<td>Cook/eat</td>
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</tr>
<tr>
<td>8pm</td>
<td>Cook/eat</td>
<td>Yoga class</td>
<td>Cook/eat</td>
<td>Eat out</td>
<td>Study</td>
<td>Out with friends</td>
<td>Ironing</td>
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<tr>
<td>9pm</td>
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<td>Watch TV</td>
<td>Watch TV</td>
<td>Bus home</td>
<td>Watch TV</td>
<td>Out with friends</td>
<td>Watch TV</td>
</tr>
<tr>
<td>10pm</td>
<td>Read</td>
<td>Read</td>
<td>Read</td>
<td>Watch TV</td>
<td>Read</td>
<td>Bus home</td>
<td>Sleep</td>
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<tr>
<td>11pm</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
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<td>Sleep</td>
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<td>12am</td>
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<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
<td>Sleep</td>
</tr>
</tbody>
</table>

* The rest is for ten minutes

In both diaries the:
walk to work or home = 20 mins
bus or taxi to work or home = 10 mins
Step 2
Start doing regular stretches

Once your routine is stabilised, you can start to carry out gentle stretches. When you have been less active for some time your muscles tighten which can result in discomfort. Stretching can reduce the discomfort by:

- Increasing the flexibility of your muscles allowing you to move more smoothly and freely
- Reducing tension and cramp
- Helping you to relax

A list of suitable stretches and how to do them is shown on pages 25–32. Choose stretches from the list for areas of your body where you feel that there is stiffness, tension or discomfort.

When to stretch

Improvements will only happen, and can only be maintained, if you stretch regularly. Start by doing stretches once a day on as many days as you can during the week: the aim is to do them every day at a time that suits you best. Some people find that it is good to stretch before and/or after physical activity such as walking or gardening. Alternatively, try first thing in the morning or just before going to bed.
Step 3
Decide on a goal and choose your exercise/physical activity

After your stretching regime has been established, which will usually take about a week, you can add a physical activity or exercise to your daily routine (which should now be stable). This exercise or activity is in addition to your current daily activities as the aim is to strengthen your body.

Highlighting what you would like to be able to do that you cannot do at present – in other words working out a long term goal – will help you decide which exercise or physical activity to add.

The exercise that you choose should be relevant and enjoyable. You should be able to do it regularly and your exercise goals should be achievable.

Enjoyable
It will be easier to keep exercising on a regular basis if you enjoy what you are doing. It could be an aerobic exercise such as walking, cycling, swimming; a home or gym based exercise programme; or just increasing things you do at home such as housework (e.g. vacuuming), gardening, or climbing stairs.

Regular
To see changes, and maintain them, exercise has to be done regularly and fit easily into your everyday life. You are aiming for a long-term lifestyle change in which you are exercising five days per week.

Achievable
Your exercise starting level must be within your capabilities: what you can do on a ‘bad day’. You want to increase the amount you do each week so your activity should be something you can break down into easy stages.

Relevant
Choose an activity which will help you. For example, you may want to be able to walk 30 minutes five times a week in order to shop.
Step 4
Set your exercise/physical activity baseline

It is very important that you carefully work out how much of your new exercise/physical activity to do during your first week of adding exercise. Start at a level that you think you can do five days a week, even on your bad days, while still managing your daily tasks and without an increase in your CFS/ME symptoms. This will be your exercise baseline.

For example, Joe can walk for 20 minutes three days per week but on a bad day he can only manage 10 minutes. Joe’s exercise baseline would be 10 minutes, five days per week. This is achievable even when he is not feeling at his best.

Important points about your exercise baseline

1. If your exercise baseline cannot be done five days per week then it is too high.

2. Some days your exercise may seem easy and it is tempting to do more. Don’t. At this stage you should stick to your exercise baseline to avoid a boom-bust pattern.

Do what you have planned to do, not what you feel you can do.

It is important that your activity is undertaken at an easy and gentle pace. Increases in exercise duration and intensity will come later.

3. You should take a short rest after exercise. This gives time for your muscles and cardiovascular system to recover before your next activity and allows you to relax. However, you should avoid resting for longer than 30 minutes, and rest in a sitting position.
What is a normal response to exercise?

You may be worried about what is a normal compared to an abnormal response to exercise. Increases in breathing rate, heart rate and sweating are all normal, temporary responses to physical activity and exercise. Your muscles can feel heavy after exercise, and you may feel physically tired. With CFS/ME these feelings of physical tiredness can be more intense, but they will also help you sleep.

A mild stiffness in the muscles is also normal after exercise and is associated with positive changes in muscle strength. It does not indicate harm to your body and will gradually lessen over a few days. A warm bath followed by gentle stretching may help you feel more comfortable.

In the unlikely event that you experience breathing difficulties such as wheezing; chest pains; or you collapse/faint during exercise, you should seek medical help immediately.

Remember to continue doing your stretches.
Step 5
Increase the duration of your exercise/physical activity

Once you have completed your first week of activity/exercise at the baseline level you can start increasing the duration of your exercise very gradually week by week. The increase in the length of time you exercise per day should be no more than 20%, an amount that your body should be able to manage. In other words, if your current exercise time is five minutes per day, then a 20% increase takes you up to six minutes (added minutes: $5 \times 0.2 = 1$ minute).

You will need to build up the amount of time you exercise to 30 minutes, five times per week, before increasing the intensity.

Don’t be tempted to do more or increase your time in less than weekly intervals; exercise at this stage should remain comfortable. It is a good idea to work out a schedule of exercise and set the target or goal that you hope to achieve each week.

On the next page is an example of the sort of exercise plan you need to make for yourself.

You may find that at the beginning of a week when you have increased your exercise time that you experience some stiffness or fatigue. Do not worry – this is a normal response to increased activity. If you continue with your exercise, and do not cut back or add any other physical activities, your body will adapt. Stretching can help to reduce stiffness so you may want to change your stretching time to after doing your exercise.

If you find that you really are not managing your increased activity comfortably by the end of the week do not increase your exercise time the following week. Instead give yourself another week or more at the same level of activity to allow your body more time to adapt. You can then set lower targets per week and increase your exercise time by less than 20%.
You may find it difficult to fit increased exercise time into your daily routine. A solution is to divide your exercise sessions into intervals and, for example, do half in the morning and half in the afternoon.

Remember to continue doing your stretches.

Joe’s exercise plan

**Target:**
Joe wishes to be able to walk for 30 minutes, five times per week, in order to shop in the High Street and return with two bags of shopping.

<table>
<thead>
<tr>
<th>Week</th>
<th>Time spent walking each day</th>
<th>Return journey to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Week 1</td>
<td>10 minutes</td>
<td>Bus stop at the end of the road</td>
</tr>
<tr>
<td>Week 2</td>
<td>12 minutes</td>
<td></td>
</tr>
<tr>
<td>Week 3</td>
<td>14 minutes</td>
<td></td>
</tr>
<tr>
<td>Week 4</td>
<td>17 minutes</td>
<td>Coffee shop</td>
</tr>
<tr>
<td>Week 5</td>
<td>20 minutes</td>
<td></td>
</tr>
<tr>
<td>Week 6</td>
<td>23 minutes</td>
<td></td>
</tr>
<tr>
<td>Week 7</td>
<td>27 minutes</td>
<td></td>
</tr>
<tr>
<td>Week 8</td>
<td>30 minutes</td>
<td>High Street</td>
</tr>
<tr>
<td>Week 9</td>
<td>30 minutes</td>
<td>High Street returning with one small bag</td>
</tr>
<tr>
<td>Week 10</td>
<td>30 minutes</td>
<td>High Street returning with two small bags</td>
</tr>
</tbody>
</table>
Once you have built up the amount of time you exercise to 30 minutes per day, five days per week, you can start looking at getting fitter by increasing the intensity of your exercise. For example, if your exercise is walking you could slightly increase the speed you walk, introduce walking up a small hill or carrying a load.

Make sure this increase in intensity is added gradually so that you do it for a short period rather than the whole 30 minutes. At the beginning, when exercising more intensively, make sure that you are not too out of breath – you should be able to hold a conversation at the same time as exercising although this may not be as easy as usual.

It will probably take you several months to work your way slowly through the last two steps of a sensible GET programme: increasing the duration and intensity of your added exercise. It is a slow process and, at times, frustrating but do keep going. If you have been inactive for a while it takes time to reverse the effects. Medical evidence has shown that the body deconditions much more rapidly than it reconditions.

Make sure that the increases in exercise that you put into your programme are very small and manageable to reduce the chances of a setback – an increase in your symptoms. If you do have a setback, do not despair. They are relatively common in people with CFS/ME and you need to develop a plan to deal with them.
Setbacks

Most people with CFS/ME have experienced, or will experience, setbacks or periods when their symptoms worsen. Setbacks can occur for many reasons but particularly overdoing it mentally or physically, or having an infection such as a cold or flu. It is important to have a plan to deal with a setback in order to maintain the improvements you have already gained.

You must first establish the cause of your setback as this will make a difference as to how you deal with the problem. There are two types of setback: CFS/ME related and non-CFS/ME related. It can be difficult to distinguish between them as the symptoms are often similar. For example, a sore throat and physical fatigue can be symptoms of CFS/ME or a cold. There may also be times when you just cannot work out why a setback has occurred. However, if you can work out why a setback has happened you can lessen the chance of it recurring.

On the whole, if you have the typical symptoms of an infection such as an increased temperature, runny nose and a cough, then you probably do have a cold or flu and your setback can be classified as non-CFS/ME related. Joint or muscular injuries such as a sprained ankle are also non-CFS/ME related.

In a CFS/ME setback one or more of your CFS/ME symptoms will be worse. This could be related to a number of things such as sleep disturbance, emotional distress or exceeding your programmed level of exercise.

If you are not sure of the origins of your setback ask your GP for advice.

Managing a setback

Once you have identified a setback as either CFS/ME related or not, you can follow the Managing a setback diagram on pages 22–23.

If your setback is not CFS/ME related, in other words you have picked up an infection, you should reduce the amount of exercise you do, or even stop altogether for a short while, before returning to your GET programme.
If your setback **is** CFS/ME related then you should try and continue exercising at your current level to the best of your ability.

It is often incorrectly assumed that an increase in symptoms equals harm. It doesn’t. If you continue at the exercise level you are on now you may well find that you feel no worse, and after a short while you may actually feel better. Remember that although you may not feel like exercising during a CFS/ME related setback, by resting too much you can quickly lose the physical gains that you have made.

Setbacks are a normal part of recovery and so it is important to remain as positive as possible. As you get stronger you will find that you have fewer setbacks and they are less severe and last a shorter time.

**Forming a setback plan**

Managing a setback is a matter of using common sense but you will find it helpful to work out a plan of action in advance.

When developing a setback plan there are important points to remember.

- Try to maintain as much physical activity as you can even if this seems difficult.
- Resting too much will probably worsen your condition in the long run. Even resting for a week can make it much harder to get back to where you were on the GET programme.
- If you cannot do your exercise in one go break it into two or more sessions.
- If you have had to stop an activity or an exercise get back to it as soon as you can.

On the next page is a setback plan worked out by Joe who, you might remember, is aiming to walk for 30 minutes to reach the High Street and return with two bags of shopping. Joe is currently walking to the coffee shop and back, a return journey of 17 minutes, five times per week. However, he has had a busy time recently, with family staying and a few late nights, which has caused an increase in his symptoms that could be classed as a CFS/ME related setback. Joe now follows his setback plan to keep up his exercise levels and avoid deconditioning.
Joe’s setback plan

1. I will try to continue walking for 17 minutes on five days per week even though this will feel more difficult.

2. If necessary, I can walk at a slower pace or rest for five minutes at the coffee shop on some days.

3. Alternatively, I can break down the walk into two sessions, i.e. do 10 minutes in the morning and seven minutes in the afternoon on some days.

4. If I am unable to manage five days of walking for 17 minutes, even with rests or by splitting it into two sessions, do one of three things:
   • Do the 17-minute walk four times per week, instead of five, and continue to split the walk or take rests as necessary or
   • Return to the previous step of my exercise programme - walking for 14 minutes. Do this for one or two days, and try to do the 17-minute walk on the other days or
   • Walk for 14 minutes for the next five days.

5. I should aim to return to the 17-minute, pre-setback walk as soon as possible.
Managing a setback

Symptoms typical of CFS/ME, e.g. fatigue, headaches, sore throat, tender glands, concentration and sleep problems:

**CFS/ME related setback**

Aim to stay at present exercise level for one week until feeling better

Possible

Not possible

Use your setback plan

Continue to the next level of your GET programme
Increased symptoms

Symptoms typical of infection, e.g. raised temperature, runny nose, phlegm production:

**non-CFS/ME related setback**

Is medical help necessary?

Yes - see your GP or pharmacist for medication

Stop exercising until your symptoms have reduced.
When feeling better start your GET programme again at a manageable level.

Use your setback plan if necessary

No
Conclusion

This guide to undertaking a GET programme has outlined the basic principles involved, namely stabilising your daily routine and introducing stretches and exercise in small weekly increments.

Before starting a GET programme you must discuss it with your GP or hospital doctor and keep them informed of your progress throughout.

In order to maintain the benefits in the long term it is important that you continue to exercise regularly. GET has been shown to reverse the deconditioning cycle, and the consequent reconditioning of your body will help to improve many aspects of your life including fitness, sleep and mood. The skills that you have developed through following a GET programme can be used to set up and achieve future goals as the discipline involved in sticking to the programme gives you more self-confidence.

The positive effects of GET can last at least two years (or even longer – no studies have tested this yet) and success will give you a greater chance of controlling your symptoms rather than CFS/ME controlling you.
Stretching exercises

At the beginning choose two to three stretches that target your personal areas of stiffness. You should feel a gentle stretch in your muscles but it should not be painful. When you start to feel the stretch you should hold the position for 2–5 seconds.

Over the weeks you can gradually increase the length of time you hold the stretch, for up to 20 seconds. You can also increase the number of times you do the same stretch, up to three times per session.

If you find stretching particularly helpful you may like to do your stretching routine more frequently, for example two to three times a day. However, make sure that you build up the number of times you stretch very gradually. You can also add different stretches, up to six per session.
1. Standing calf stretch

Stand in front of a wall and put your hands flat on the wall as shown. Stretch your right leg out straight behind you, keeping your heel on the floor, and slightly bend your left leg. Keeping your back straight, bend your left knee over the centre of your left foot, keeping both heels on the floor. Hold the position when you feel a stretch in the calf of your straight right leg. Repeat with your left leg behind you.

2. Deep calf stretch

Stand in front of a wall and put your hands flat on the wall as shown. Place your right leg behind and slightly to the right side of your left leg. With both heels on the floor, bend both knees until you feel a stretch in the calf of your right leg, low down near the ankle. Repeat the exercise with your left leg behind.
3. Standing thigh stretch

Place your left hand on a wall for support and stand with your back straight, chest lifted and your tummy held in. Your feet should be hip-width apart.

Take your weight on to your left leg and bend your right leg until you can hold your foot with your right hand. Bring the heel of your right foot against your bottom as shown. Keep your back straight, your knees together, your supporting left leg slightly bent, and your right knee facing the ground.

Gently press your hips forward until you feel a stretch at the front of your right thigh. Repeat by holding your left leg up.

4. Lying thigh stretch

Lie on your right side with your legs bent and your head resting on your right arm. With your free arm take hold of your left foot and gently draw your left heel towards your bottom. Tilt your hips forward at the same time and you will feel the stretch in the front of your left thigh. Repeat with your right leg by lying on your left side.
5. Standing hamstring stretch

From a standing position, stretch your right leg out in front of you and place your foot on a small step. Keeping your heel on the step, lift up your foot up so that your toes are pointing to the ceiling. Keeping your back and right knee straight but your left knee slightly bent, put your hands on your hips, stand tall and then lean forward from the hips, sticking your bottom out as though you were going to sit down.

You should feel the stretch behind your right knee and thigh, as your left knee bends a little more. Repeat with your left leg on the step.

6. Seated hamstring stretch

Sit on a chair and put your right leg on another chair set in front of you. Bring your right foot towards you so your toes point upwards. Put your hands on your hips and, keeping your head up and your back straight, sit upright and then lean forwards from the hips.

You will feel the stretch in the back of your right leg. Repeat with your left leg on the chair.
7. Seated groin stretch

Sit on the floor in the position shown with the soles of your feet touching each other; you may need to move your feet away from your groin to make this more comfortable. Keep your back straight, look straight ahead and put your hands on the inside of your knees.

Gently push downwards until a stretch is felt down the inside of both upper thighs.

8. Seated hip and back stretch

Sitting on the floor, stretch your left leg out in front of you. Bend and cross over your right leg so that your right foot rests against the outside of your left knee. Put your right hand on the floor behind your right hip so you can support your upper body. Use your left hand to slowly pull your bent right knee towards the midline of your body. At the same time twist from the waist to look over your right shoulder keeping your head up.

You will feel a stretch down both sides of your body and on the outside of your right buttock. Repeat with your right leg stretched in front.
9. Side stretch

Stand straight with your feet shoulder length apart and your knees slightly bent. Hold your right arm up in the air and, keeping your arm straight and your head up, move it towards your left side over the top of your head as you slide your left arm down your left thigh. You will feel a stretch down the right side of your body. Repeat with your left arm held up.

10. Back stretch

Sit down with your legs crossed as shown. Put your hands flat on the floor in front of you and move them forwards letting your back bend. Keep your shoulders relaxed and your head down in line with your spine. You will feel a stretch along your back and shoulders.
11. Triceps stretch

Sit on a chair and look forwards with your feet flat on the floor and your back straight. Lift up your right arm and place your palm just behind your right shoulder. Place your left hand on your right elbow and push backwards. You should feel a stretch along the back of your right arm. Repeat with your left arm lifted up.

12. Shoulder stretch

Sit on a chair and look forwards with your feet flat on the floor and your back straight. Extend your right arm across your chest so your arm is parallel with the floor. Keep your shoulders relaxed and facing forwards. Put your left hand on your right elbow and move your arm towards your chest until you feel a stretch in your shoulder. Repeat with your left arm across your chest.
13. Chest stretch

Sit on a chair and look forwards with your feet flat on the floor and your back straight. Hold your right arm out behind you and, keeping your thumb up and your palm facing outwards, slowly move your arm backwards without twisting your body.
Relax your shoulders and when you feel mild tension in the right side of your chest, hold the stretch. Repeat with the left arm.
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