Self-help guide to recovery for Chronic Fatigue Syndrome and Fibromyalgia

This brief guide is written in an attempt to explain the process of recovery in chronic fatigue syndrome (CFS) and fibromyalgia. Often recovery can seem to be difficult or even impossible and working out the best way forward can often seem confusing. The ideas presented here are based on an approach used by The National ME Centre. Using this approach people with CFS often achieve good results, even when their symptoms are very severe.

A pattern of peaks and troughs

On a good day (a peak), when symptoms are few, you may have a tendency to overdo it. This then later leads to a trough, in which symptoms become more severe. This increase in symptoms then leads to resting, which then leads again to a peak. So the cycle continues.

- This pattern occurs often in response to symptoms. In other words, activity levels are determined by symptoms, which are constantly going up and down.
- The cycle may occur on a daily, weekly or monthly basis.
- It lengthens the illness and may even lead to deterioration.
- A general rule of thumb is: the more you push yourself the more you relapse. It is therefore important to achieve a balance between activity and rest.
Causes of relapse

People with chronic fatigue syndrome or fibromyalgia, characteristically follow a cycle of relapses and remissions. Certain factors can cause a relapse or worsening of symptoms:

- Excessive alcohol
- Immunisation and vaccination
- Infection
- Psychosocial stress
- Surgery or trauma
- Anaesthetics, general or local

Attempts at recovery

- In an effort to get better, it can be tempting to try to push yourself to the limit.
- In reality this can lead to going backwards.

Activity baseline

To reduce the peaks and troughs it can be useful to establish an activity baseline. This may take some weeks to achieve. It is:

- A comfortable level of activity that can be managed on a regular basis.
- It can be pitched somewhere between what is achieved on a ‘good day’ and a ‘bad day’.
- It is often useful to keep an activity diary to monitor progress and setbacks. Sometimes after a setback, through for example illness, a new baseline will need to be established at a lower level of activity. Use setbacks as a learning experience and don’t be too hard on yourself.

Steps to recovery

- It is often much more helpful to adopt a step-by-step approach to recovery to try and eliminate the peaks and troughs.
- Graded activity. It is important to set goals for yourself. These are made in relation to where you are at any moment in time. Goals also
need to be realistic. You may work on one goal for quite a few weeks before it is achievable. Only when it is comfortably achieved are you then ready to move onto the next step. It is also important to build up activities across the board in areas that have meaning for you. This means deciding which areas in your life are important to you, and in small manageable steps work towards goals in these. An example might be to go to town shopping. To start with, short walks may be taken, which are gradually increased over the weeks in length. A trip on the bus to town and back may then be taken. Over the weeks the time spent in town can then be very gradually increased with maybe just one shop being visited initially for 5-10 minutes.

**Daily programme**

- A daily routine can help to reduce the peaks and troughs, to gain consistency in activity levels and symptoms, and to better manage your energy.
- It consists of regular times for getting up and going to bed (to help re-establish a sleep pattern), and a balance between rest and activity.
- The programme very much depends on the symptoms experienced, with the aim being to avoid overstretching. Sometimes initial restrictions and losses lead to long-term gains. This means that, at the start, activity levels often have to be reduced from what has been your normal routine. This is to find a baseline in which peaks and troughs are no longer experienced. In the long term, however, with a gradual building up of activity, activity levels can go beyond current levels.

Use the space below to think about your current daily routine. How could you improve it in an effort to reduce your peaks and troughs?
Sensory overload

- Sensory overload is when the brain is ‘bombarded’ by more stimuli (sensory inputs) that it is comfortable with.
- When this occurs it has difficulty in distinguishing between important and unimportant information.
- The stress response, or ‘fight and flight’ response, can be constantly activated at a low level, which is draining on the body’s energy stores. Common examples are supermarkets where there are bright lights and lots of choice, computer games, etc.

Rest = relaxation

- Rest means on a neurological level. In other words, relaxing the body and mind. Often, when sat at rest our minds can be very active. For example when thinking something through it is as if we have a ‘mental video’ playing in our mind. If we watch of rehearse distressing thoughts, this can lead to activation of the stress response. This means our bodies respond as if the event were really happening, although to a lesser degree. The good news is that nice thoughts also work in this way, but have a positive effect on our bodies. States of appreciation are emotional states in which we experience and enjoy the pleasure of feeling good. These states can be a solution to the negative effects of distress, for example, through enjoying a wonderful sunset. Alternatively visualisation can be an excellent way of achieving states of appreciation. Imagining ourselves doing something special, or anything that gives us that ‘nice glow’ feeling inside can do this. It can be helpful to use all the senses, so include how the experience sounds, feels (e.g. the ground under your feet, the warmth of the sun, etc), looks, smells and tastes.
- Switching off both physically and mentally equates to a ‘downloading’ or ‘recharging’.
- A lot of leisure activities are not deeply relaxing (e.g. watching TV). Although these are important in line with your everyday activity, some deep relaxation needs to be built in on a daily basis.

Relaxation

Among different deep relaxation techniques you might consider doing are:
- Breathing exercises.
- Physical relaxation (e.g. tapes).
- Autogenic techniques – these are a system of very specific auto suggestive formulas (e.g. my heart beats calmly and regularly). These help calm the mind and body.
- Soft music (preferably without words).
- Guided imagery and visualisation.
- Meditation.
• Meridian therapies.

Activity

• It is important to gradually increase levels of activity once a baseline has been established, with the elimination of peaks and troughs.
• Activity can be physical, cognitive, social and emotional.
• It must be meaningful and purposeful to you.

Pacing

• This is the key to recovery.
• It is a daily balance between rest and effort.
• It involves a balance of activity through the day and throughout the week.
• Complex tasks that lead to ‘troughs’ need to be broken down into smaller manageable tasks. The aim is to do tasks with minimum effort and not to go into a ‘trough’ afterwards.
• The energy requirements of tasks can be broken down into low, medium and high and a mixture of these should be balanced through the day and week. For example if too many high-energy tasks are done, or one is done for too long, a trough will occur.

How could you break down some of your complex daily activities so that you do not enter a trough? What sort of things could you do to rest between these complex tasks?

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Goal planning

• Goals need to be both daily and weekly and it is also useful to have long-term aims, although some flexibility may be needed here. In other words it is useful to have guidelines rather than definite plans, as life very rarely goes strictly to plan. Be flexible and persistent in working towards your aims, which need to be realistic.
• Work on the daily goals in order to, gradually over time, lead to steps of progress.
Thoughts and feelings

- Sometimes people hold beliefs that can slow recovery, e.g. ‘If I try to move forwards I will always relapse’. Negative thoughts can be challenged and a ‘thinking diary’ may help here. Write down a counterargument or positive alternative for every negative thought. One example is, ‘I know my body is working to repair itself and with good pacing it can achieve this’.

- Increased worry, anxiety and mental activity can lead to sensory overload, which impedes recovery. In order to decrease internal arousal, if possible, work through problems in counselling, with a good friend or in a personal journal.

Reducing activity

- Often as symptoms increase, people do less. They can then get secondary problems from being inactive.

- Once a baseline has been established, with the peaks and troughs being better managed, the aim is to set goals that gradually increase activity tolerance. This helps to reduce symptoms, and improve confidence and control over the illness.

Summary

“I used to take two steps forward and three steps back. Now I just take one step at a time” (RO 1996).