

POST-VIRAL FATIGUE SYNDROME:

Managing Your Energy



One of the most important skills to learn to help you cope and reduce your symptoms of post-viral fatigue syndrome (PVFS) or chronic fatigue syndrome (CFS) is activity management and energy conservation.

Activity management is a way that can help all of us balance our daily activity between doing things and resting. It is especially useful if you have PVFS/CFS as your energy stores are much lower and, therefore, balance becomes even more important.

STAGES OF THERAPY

We aim to work with you through the three stages of the therapy programme below, supporting you to gain control and improve your quality of life.



Stabilisation

- Understanding and acceptance
- Reducing 'boom and bust'
- Introducing regular relaxation
- Improving sleep and reducing symptoms



Increasing tolerance

- Gradual increase in activities
- Introduction of/increase in exercise
- Looking at difficult thoughts and feelings
- Managing demands of others



Maintenance

- Wellness plan/progress summary
- Plans for sustainable increases in activity, exercise, work and/or school
- Coping with setbacks
- Future goals/things you wish to still work on

This process will be different for everyone as people start at varied levels, and people's life circumstances are very diverse.

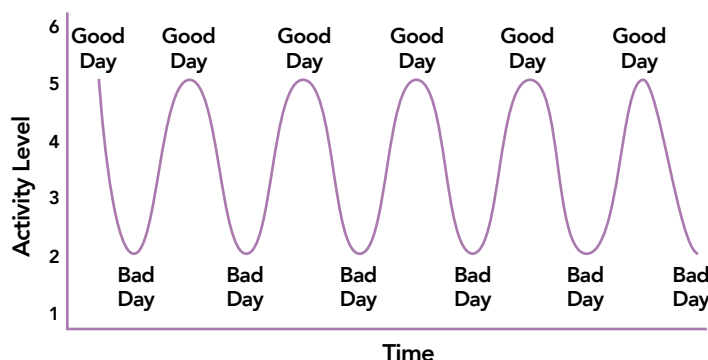
STABILISATION

Most people tend to do a lot when they feel good and reduce activity when they feel unwell (See the Boom and Bust Activity Cycle diagram below). This can lead to swings in activity and if you have PVFS/CFS you may find that you over do things on one day and then need several days to recover. This is often referred to as a **boom and bust activity cycle** and can actually lead to decreasing levels of activity.

To reduce boom-and-bust patterns of activity and

stabilise your energy levels, your healthcare team will help you to understand your current activity patterns. Completing an activity diary will record the type of activity you do, your energy levels and any fluctuations in your energy levels during the day. This will help you to make the changes necessary and establish a baseline activity level that you can sustain, without making your symptoms significantly worse. You will know this approach is helping when you start to feel more in control. The control will be good but you might feel as if your improvement has stopped and you might still have small fluctuations between 'good' and 'bad' days (See the Baseline activity level diagram below).

Baseline Activity Level

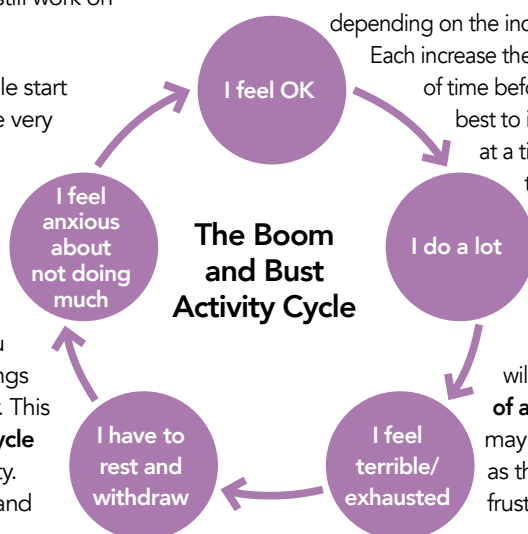


INCREASING TOLERANCE

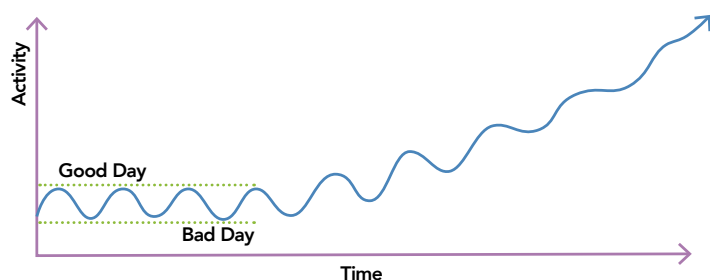
Once you have established your baseline, you will be able to introduce gradual increases in activity. It can be helpful to visualise these increases as a series of small steps. Each small increase will vary depending on the individual and how they are coping.

Each increase then needs to be sustained for a period of time before a further step is taken. It is usually best to increase only one or two activities at a time; for example, extend reading time by a few minutes and add one minute to a daily walk. Trying to increase activity in every area of your life simultaneously could be challenging.

Over time these small increases will add up to an overall **improvement of activity levels**. Keeping a record of this may help you to see the improvements as they are small and may seem frustrating at the time.



However, patience will pay off in the long run.



Balance Different Types of Activity

Balancing different types of activity is also important. Types of activity can be referred to as 'physical' (involving mainly movement), and 'cognitive' (involving concentration, memory and mental processing).

Examples of physical activity are:

- getting dressed
- taking a walk
- making a meal
- gardening
- collecting children from school
- going to the shops.

Examples of cognitive activity are:

- watching TV
- using a computer
- phone calls
- having a conversation
- reading.

Balancing means not doing any type of activity for too long – the length of time will vary according to your symptoms. It may be helpful to break up tasks into manageable chunks and take breaks in between.

Good quality rest and relaxation is an essential part of your activity management and your therapist can advise you on stress management and relaxation techniques.

The activities you are gradually increasing should be across a wide range of areas including enjoyable activities/interests, personal care, housework, family commitments and employment or community activities. It is not all about exercise but we do encourage people to start including a little exercise in their daily activities.

Exercise Therapy

Exercise therapy involves a structured activity management programme that aims for a gradual increase in activities (including aerobic exercise at the right point of recovery). Exercise may not be for everyone and is not a cure for PVFS/CFS. Some people choose to try physical activity as it can help them feel better. This should be an individualized program designed for you by a medical professional.

The key principles are as follows:

- Find a stable baseline of activity/exercise that can be managed six days per week and not just something that can be achieved on a 'good day'.
- Expect increasing activity to cause a minor increase in

symptoms, but reduce the increase if symptoms are severe or prolonged.

- Increase activities in gradual 10–20% increments after an activity has been successfully maintained most days for a period of around 2 weeks. For example, increase a 10-minute walk to 11 minutes, so increments are small, steady and sustainable.

For more information about exercise therapy, see the Exercise Therapy leaflet.

MAINTENANCE AND GOAL SETTING

Setting goals is an important part of maintaining and improving your activity levels. Goals are clear statements of your planned steps to move forward and will obviously vary from person to person depending on the level of illness.

Some examples include:

- walking to the local shop (10 minutes every day);
- managing to vacuum a room;
- meeting a friend for a coffee once a week;
- reading a book for an hour;
- doing a craft activity for 30 minutes;
- enjoying some gardening;
- reading for 10 minutes each day;
- reducing daytime sleep to 1 hour; or
- two stretch exercises done once a day.

How To Set Goals

- Choose a goal that will give you enjoyment or achievement.
- Be realistic about what you can achieve.
- An activity diary is a helpful way to record your current ability and help you set a baseline.
- Break a large/long-term goal down to attainable chunks.

For example, with a goal of meeting a friend for a coffee initially this could be at home for 30 minutes and then the time could be extended over several weeks before moving to meeting elsewhere.

Write your goals down, and display them somewhere obvious at home and get some support from friends and family.

Goals Should Be 'SMART'

- Specific:** Is your goal too vague?
If so try to be clearer about it.
- Measurable:** How will you know if you have achieved your goals?
- Achievable:** How likely are you to be successful?
- Realistic:** Are you considering the challenges involved?
- Timed:** When will you review your progress?

Goal setting and how to achieve it can be discussed more with your physical therapist and team of doctors. Your therapist can also help you with more detail about pacing and graded exercise therapy ensuring you are moving in the right direction!

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