

I have written the Exercise Guidance Note below, which is intended to be a short summary of exercise issues in ME/CFS and contradict the Graded Exercise Treatment. I hope it can be easily read by doctors and patients. The pacing program and other statements are adapted from Dr Lewis's book (Reference 2.) The article has appeared in Emerge, Summer issue (<http://www.mecfs-vic.org.au/emerge-magazine-0>).

For those of you who are not readers of Emerge, here it is.

– Susanna Agardy

EXERCISE/ACTIVITY GUIDANCE NOTE

FOR Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Compiled by Susanna Agardy

People with ME/CFS react to exercise/activity differently from healthy people. While healthy people and even those with other medical conditions find exercise invigorating and strengthening, people with ME/CFS are unable to sustain activity/exercise for normal periods and become exceptionally exhausted. Exhaustion may set in immediately or it may be delayed by as much as one or two days. This reaction is called payback or post-exertional malaise. It may be triggered by relatively minor physical exertion such as a walk, attending a family function, or mental effort and stress which could have been easily tolerated before the onset of ME/CFS.

Post-exertional malaise is the most exceptional feature of ME/CFS. Other common symptoms are: fatigue, sore throat, cognitive dysfunction, sleep disorder, pain, inability to stand for any length of time (Orthostatic Intolerance), sensitivities to food, drugs and chemicals, and many others. Exercise may be followed by exhaustion and additional pain, with tingling and twitching of muscles. Many other symptoms may also get worse, even symptoms which are not normally thought of as being the result of exercise (e.g. cognitive dysfunction). Recovery may take days or weeks, depending on the extent of exertion. For this reason, levels of activity which are excessive for the particular person cannot be repeated day after day without risk of serious relapse.

Research has shown that symptoms of ME/CFS are related to impaired immune, neurological and hormonal responses, infections, mitochondrial dysfunction, channelopathy, oxidative stress and more. There are heart, brain, muscle and other body system irregularities. The aerobic pathways in people with ME/CFS are also damaged. These make it impossible to maintain and recover from exercise in normal fashion.

People with ME/CFS are affected to varying degrees, with varying exercise capacity and with differing symptoms. Some are able to work, some are capable of moderate activity such as shopping and social activities, while others are housebound or bedridden. The condition can fluctuate and people with ME/CFS can improve significantly, some remain the same for many years, while others become worse.

Recommendations of Graded Exercise Therapy (GET) for ME/CFS are controversial and are mostly based on the assumption that the illness is the result of dysfunctional thought processes, abnormal illness behaviour and physical deconditioning. Studies of GET do not ensure that the participants included suffer from serious symptoms of ME/CFS such as post-exertional malaise and mostly use loose, fatigue-based criteria, allowing mixed groups of fatigued participants to be included. Although overall improvement of fatigue is usually reported, there is no evidence in any study that GET improves post-exertional malaise and other symptoms of ME/CFS. Possible adverse effects are ignored even when there

are high rates of dropping out and non-compliance. More seriously affected people would be unable to participate in such studies, yet, the results are generalised to them. Recommendations for GET ignore the risk of harm indicated by other research and the frequent worsening of symptoms following exercise reported by people with ME/CFS.

There are many medical issues to be addressed in ME/CFS and some treatments may assist although there is no cure. A health professional who is knowledgeable about the illness should be consulted. Managing total activity levels is one essential step in dealing with the illness. This includes self-care, housework, employment, social activities and mental activity as all activity makes demands on energy. The level of activity/exercise needs to be carefully managed at all phases of the illness to avoid deterioration. It needs to be accepted that many people with ME/CFS may not regain their pre-illness capacity.

Pacing, or keeping within your boundaries, is designed to ensure that you do not overdo activity/exercise and at the same time avoid deconditioning. Pacing, as shown in the steps below, is recommended:

- Establish the total exercise/activity level you are capable of without any payback or post-exertional malaise. A pedometer or actimeter may be helpful in measuring the amount of physical activity you have done on any day.
- To begin with, you need to do less, so that eventually you increase the chance of doing more.
- Maintain the level of activity/exercise that you can manage and stay on this plateau until you have a reserve of energy. The correct level of activity/exercise is that which can be repeated the next day without any payback.
- Do not move to the next level of activity/exercise until you have the reserve which enables you to increase your activity level without payback.
- Repeat the pattern of staying at the next plateau of activity/exercise until you are able increase it without payback. You may reach a limit which should not be exceeded. You may need to stay at this level of activity.
- Balance physical and mental activity with rest, dividing activity into short segments, alternated with rest. Rigid schedules of activity/exercise should be avoided and activity should be tailored to your level of ability.
- If you have overdone activity/exercise or suffer a relapse for any reason, decrease your activity/exercise and rest more. Repeatedly overdoing it may cause a severe and long-lasting relapse, bringing with it a worsening of many ME/CFS symptoms.
- You need to do the correct type of exercise:

Aerobic exercise can be damaging and should be avoided unless you can already do this every day without payback. Aerobic exercise includes running, swimming and cycling - any exercise which causes an increased heart-rate;

Anaerobic exercise is recommended. This involves exercise such as lifting and stretching, which can be done more easily without payback.

Listen to your body, do not push beyond your limits and get plenty of rest!

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