

# EXERCISE IN CFS

One of the problems experienced by those suffering from Chronic Fatigue Syndrome is difficulty in taking exercise. Among the difficulties in this illness, the aggravation of symptoms with more than minimal exercise can be one of the most frustrating. We know that in any illness total inactivity leads to muscle weakness. Even one day in bed with flu can turn the muscles into a jelly-like state. Inactivity causes changes in muscle chemistry such as a lowering of muscle carnitine levels, poor circulation, loss of tone, loss of muscle bulk and subsequent weakness – making efforts at rehabilitation extremely hard.

It has been shown in research that in CFS there is an imbalance between the short acting and endurance fibres in the muscles, with a preponderance of short activity fibres, which helps to explain the inability to sustain exercise. Many report that they are able to do a short burst of activity but rapidly run out of steam. Poor circulation (due to low blood pressure, lowered blood volume etc) means that oxygenation of cells and lactic acid build up becomes more likely, so pain (myalgia) may develop. Also an ion channelopathy means that the exchange of ions of different chemicals in and out of cells may be deficient. All this helps to explain some of the total muscle exhaustion frequently experienced by those with CFS.

Many people who get CFS will have been exercising very hard at the time of onset, and many top athletes are at risk of developing CFS if they continue to train or resume sport at a time of viral illness, such as flu or glandular fever. In these people the physical stress has been an added risk factor in an already vulnerable individual. We know that people who try and exercise too much as part of their rehabilitation in CFS run a serious risk of relapse or long term continuation of their illness. There is often an unrealistic striving for excellence.

A lot of research into Chronic Fatigue as opposed to CFS has shown that exercise can be beneficial, but it is important to differentiate between the causes of the fatigue, of which CFS is just one subgroup. For example an individual who is fatigued because of depression (fatigue is one of the main symptoms) will usually benefit from an exercise programme, and certainly a person whose fatigue is due to obesity will benefit enormously. In CFS however a very different approach for exercise prescription is required.

Many people with this illness are caught in the downward spiral of being told to exercise in order to get fitter, but human nature being what it is, tend to overexercise and risk relapse. There is a tendency to get caught in the “crash and burn” approach. This means feeling a bit better, going at exercise like “a bull at a gate” and then needing a week in bed to recover. This approach does nothing to help a person get better. Many athletes tend to get worse and worse as they continually try to get back into their sport when they are nowhere near ready.

There are several phases in this illness when the style of exercise needs adapting to give the best outcome. Initially a person can be very ill and maybe bedridden, but it is important to still maintain some activity to avoid serious muscle deterioration. This may involve just gentle body stretching and simple movement such as hand and foot wiggling, and stretching the facial muscles etc. This will all help maintain some muscle tone and improve circulation. Once the person is well enough to get up, they should be encouraged to move around the house and start on a gentle pacing-based exercise programme. This should not be construed as a “normal” approach to exercise, but just slowly increasing activities. Going to the toilet which involves walking down the passage may be enough to start with, and most people do best with several small activity bouts. As health improves the minimal activity can be slowly increased according to ability. At this stage a gentle exercise plan can be established.

I usually tell a person to think about how much they could successfully manage on their worst day – and this illness does tend to be “up and down” – and set that as their starting point. e.g. if they can walk 10 paces without problems on the worst day, this is the beginning level. The aim then is to walk 10 paces daily as a set plan for a week. If there have been no symptoms or worsening of the illness as a result, this person is now ready to move on to another level. BUT this does not mean going from 10 to 20 paces, but from 10 to maybe 12. Then gradually the exercise can be gently and cautiously increased week by week. There should be encouragement to do the prescribed exercise daily if possible, but a “day off” can be permitted each week, and this is particularly important if a relapse occurs. Other activities should be incorporated in the plan too – time outside in the fresh air (even if just sitting), deep breathing exercises and spells of total relaxation – just letting go of all the muscles and feeling the tension flow away.

This approach to exercise in rehabilitation can be used for what ever the level of health of the individual. Many say for example that they can easily walk round the block. For this person, this regular walk can then be their starting point and they can build very slowly week by week in the same way. But when ready to progress, again the gentle approach is a must – increasing from say “round the block” to that plus maybe one lamppost and back. This way the body does not get overstrained before ready. The rule of thumb should be “nothing which makes one sweat, pant or heart race or cause muscle pain”. If any of these symptoms occur, the level is too high and needs to be knocked back. Remember too that just going on walking because one feels better that day can be a trap, because there is always the return journey to complete, which may be the last straw.

It is a good idea to look on this gentle approach to exercise much as one would if embarking on a high powered gym plan. This means preparing for the exercise by making sure a small snack and drink (probably including a little extra salt) starting slowly/gently and then having an unwind time at the end – maybe lying back, doing some deep refreshing breathing and then relaxing with a nice warm drink or taking a relaxing shower or spa. This approach then becomes a worthwhile habit established for any future more vigorous exercise.

Many people ask when they will be able to resume sport, and there is no set time frame with this illness. Time and level of recovery is very variable. If a person feels ready to participate in their sporting activities again, remembering the gentle pacing approach works best. There will always be temptations to take on too much too soon. It is best to try out the sport in a very low key, non-competitive manner. Some people enjoy attending a gym, but this can have the downside of too much competition/pressure and sometimes the effort of travelling or the costs involved can be too much.

Often people ask what sort of exercise or sport is best. There is no “best” in this. Any exercise is good if moderate, and if it is to be sustained, it needs to be enjoyable and perhaps varied too. Some people like to walk or swim or dance, others prefer an exercycle or skipping rope, others do prefer the discipline of a gym, some like a gentle sport such as croquet or bowls. Getting together with others can be stimulating and help inspire the feeling of getting back into life again. But just remember never to let others push you on beyond your capability. And keep the immediate goals miniscule.

There is a very fine line in CFS between not doing enough and doing too much exercise, so starting somewhere is important. Then there is the maintenance of the effort without trying to progress too rapidly – think of it as if walking a tightrope – trying to go too fast will cause a spill, but lingering too long before starting means you may never succeed and instead wobble off, and lose courage. It’s a bit like riding a bike down a steep hill too, keeping the brakes hard on and you arrive intact, but let them off too soon and you are in an injured heap at the roadside!

#### **What are the pitfalls?**

- Lack of motivation
- Trying too hard too soon
- Giving up too soon
- Being pressured by others
- Setting goals too high
- Depressed by loss of fitness and lack of ability

#### **What are the benefits?**

- Improved muscle tone and strength
- Weight control
- Enhanced mental wellbeing
- Better circulation
- Better sleep
- General health improvement