

The benefits of exercise

By Amanda Arthurton

I am writing this as I had promised myself that if I managed a year without suffering a period of extreme fatigue, (other than that associated with an infection), I would try to make the advice which I have followed, and found so beneficial, accessible to others. So with a bit of background to put it in context, here it is.

I have Sjögren's Syndrome. Bouts of extreme fatigue have been the symptom which has proved hardest to manage. I have always been a keen hiker, but had got into a downhill spiral of feeling profoundly fatigued and needing a day or two in bed and another day or so off work, apparently recovering, then overdoing it, (by not doing that much, but being completely unaware that it was too much at the time), and then feeling even worse. These episodes were always heralded by a slight sore throat, which for some years misled me into thinking that I had an infection. Stepping down from my post as head of the mathematics department in a secondary school, and a year or so later dropping to a four day week on a lighter timetable helped, but not nearly as much as I had hoped.

In despair one day in July 2007, after a bout of fatigue, which forced me to cancel my holiday as I could not pack without having to sit down repeatedly, I re-read my Sjögren's Syndrome handbook and decided that I was 'deconditioned'. I turned to a physiotherapist friend for advice. The ten minute phone conversation that followed has been so massively beneficial to me, that I would like to pass her wisdom on.

As my G.P. commented, it is the sort of advice that is given to people who have M.E.

It was based on a very, very gradual build up of cardio-vascularly demanding exercise and then maintaining it. It was very straight forward. Just walk briskly for half a minute then at an ordinary pace for one and a half minutes, repeat this five times and then stop. (New runners I believe do something similar, but they run and walk.) The next day increase the number of repetitions slightly, the next day a bit more, etc. It was as simple as that. So successful was this that at the end of the school summer holiday I climbed Helvellyn, one of the highest mountains in the English

Lake District, via Striding and Swirral Edges. This summer (2008) I had a walking holiday in the French Alps.

In order to maintain my fitness I try to do a workout at home two or three times a week and/or have a good walk. I don't have time to go to a gym, and anyway I dislike them. The workout is very much my own concoction of exercises, and again it was built up very slowly and carefully. In case it is of interest this is what I do: 20 alternate straight leg raises, 20 side leg raises and 100 'bicycles' lying on my back. Then lying on my front I raise my straightened right leg and left arm together a couple of inches off the floor, and alternating with the other arm and leg, repeat this 20 times. Then I do 10 push-ups, some yoga exercises and, on a good day, climb the stairs 20 times in succession.

Whilst recognising that not everyone wants to be fit enough to walk in the mountains, or may not be able to get that fit, I pass this on because, although I felt it must be possible, I really did not know how to improve my own health. Having in the past loved hiking and always been able to exercise, with no ill effects, even if I had done nothing for a fortnight, I had not realised that now with this 'altered self' very regular exercise would be the key to avoiding prostrating fatigue. However having said all this I still need a lot of rest, half an hour or so at some stage in the afternoon and nine and a half or ten hours in bed every night, to pace myself carefully, to minimise stress and to avoid overdoing it. If I get a cold I am really knocked out. It usually means two and a half weeks off work, and then very gently rebuilding the exercise program. But, for over a year, I have lost no work time purely because of fatigue, which has been a huge step forward.

At St. Thomas' Hospital's Lupus Clinic my doctor said he thought that many patients do not realise how important frequent, regular exercise is. Certainly I did not. However, as I said to him it is very hard when you try to be active, and unaware that your underlying strength is inadequate, overdo it and are prostrated. We really do need detailed advice about how to break such a cycle. When I suggested that maybe a leaflet could be written for patients, he suggested that I and my physio friend should write something.



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She has kindly provided a more general blue print for getting going, so here in her words it is. "The concept you need to apply is called 'pacing'. It is much more about doing things little and often or in bits and pieces, rather than attacking the whole activity at once. Once mastered it is a skill that could offer you much more control over bouts of fatigue and flare-ups, allowing you to make and keep to plans much more reliably, breaking the good day/bad day, boom/bust cycles. This is how it goes:

- Choose an exercise or functional activity that is important to you.
- Now time yourself and try to do this exercise/activity until you feel a physical change (e.g. muscles aching, out of breath, fatigue, pain etc.), do NOT wait until you cannot do it any more.
- This time is your base line and your pacing activity starts at 75% of this (say you had walked for 8 minutes before the change occurred, your baseline activity will be 6 minutes of walking).
- Do this base line activity for 2 or 3 days.
- Then increase the activity by a small increment every 2 or 3 days, in this case about another minute of walking.
- Continue with increments at a slow steady pace until you achieve your goal.
- Continue exercising regularly at this level.
- When you have a flare up do not go back to the base line or even zero, but drop back by a few increments (you are the best judge of how weakened by the flare you have been), once it is over you can increase the increments at the same speed as before.
- The aim is always to put yourself in control of your stamina (as far as that is possible), and so to be able to plan with greater confidence.
- You could keep a diary or chart to use as a marker and motivator
- Once one aim has been achieved another can always be embarked upon.
- RULE: never take short cuts and stop the incremental nature of the approach, however tempted you feel (on a good day) to jump a level or two, if you do you are relinquishing control and likely to succumb to 'pay back' from that altered self."

I hope that this combination of personal experience professional advice may help at least one other person. If it does it will have been well worth writing. My physio friend didn't wish to be named, but I have been very grateful to her for her help with this.

Comments from Dr Elizabeth Price, BSSA Trustee & Medical Council Vice President: The 'deconditioning' described by the author is a well recognised phenomenon. It occurs in conditions such as fibromyalgia and ME as well as in the rheumatic diseases and is commonly seen after acute debilitating illnesses and post-surgery. In essence muscles and the body in general become less 'fit', it then takes more effort to do something, there is a tendency to do less and it becomes a downward spiral. Regular, initially very gentle exercise, gradually re-building stamina is the answer. There have been some clinical studies looking at this & showing that graduated exercise programmes do work.

