

The Potential Benefits of Neurophysiotherapy

This is the experience of a severely affected ME patient who had neurophysiotherapy at home. A sympathetic neurophysiotherapist visited three times a week for 8 years. The length of each session varied according to the patient's capacity on the day. The input of the neurophysiotherapist helped the patient progress from being bedridden, requiring around the clock care and having nursing care needs, to being able to walk a little with a frame.

At first, when very severely affected, the following input from the neurophysiotherapist helped: -

- Pain relieving massage of neck, shoulders, back and legs
- Stretching the feet and manipulating the ankle joints, due to a contracture of the Achilles tendon and severe 'foot drop' (acquired during an inpatient hospital stay - this had been treated with Botox)
- Splinting the feet, again to help stretch the Achilles tendons
- Passive joint mobilisation to help prevent further contractures
- Chest physiotherapy to improve breathing and to move any mucus which may have accumulated due to lack of movement and shallow breathing
- Very gentle passive exercises, with the neurophysiotherapist moving all limbs

The patient's carer was taught how to carry out the passive exercises: however, this was as an interim measure for days the neurophysio did not visit, rather than instead of physiotherapy sessions.

As the patient's health improved and they had a little more energy the neurophysio worked on active assisted exercises *i.e.* the patient actively participating in the limb mobilisation. This was used to help with very simple activities of daily living, such as picking up a cup from the table at the side of the bed to have a drink. The patient was taught to roll, aiding positioning for comfort and personal care in bed. Muscle memory was very important. The patient was also taught to sit unsupported in bed, when the time was right.

As the patient further improved, the neurophysio worked at sitting the patient on the side of the bed, before standing up at the side of the bed.

When it came to walking, again muscle memory was very important. The patient was unable to lift up their feet. Rather than the neurophysio walking the feet forward a few steps (as had been tried before unsuccessfully in a hospital setting) the neurophysio lifted the patient's foot and placed it first passively until the patient was actively able to participate. This continued until the patient was ready to try to walk a few steps with a rollator. This process took several weeks.

The physiotherapist arranged for a suitable NHS indoor and outdoor powered wheelchair for the patient. This had to be adapted to reduce vibration.

One of the final things the physio did was to sit the patient in the chair. This had to be done with the neurophysio standing in front of the patient as the patient had a tendency to fall forward from the waist and had no sense in advance that this was going to happen: the

patient would then be unable to sit themselves back up. Often non specialist physiotherapists seem to prioritise sitting upright in a chair. During an inpatient stay this had been done to the detriment of the patient's health. For this patient sitting up in a chair felt very taxing, in fact it was the hardest thing to do.

This patient was also in the fortunate position to have the support of an understanding consultant with good awareness and a specialist interest in ME, as well as a family member providing appropriate care. This combination, together with the neurophysiotherapy input, allowed the patient to progress.

As stated, the patient was unable to move, was bedridden and reliant on a family member for around the clock care. After 8 years they were spending brief periods out of bed - e.g. 30 minutes sitting in a chair - and were largely self-caring, using a wheelchair to get around indoors and in the garden and managing some activities of daily living such as a very small amount of washing up while sitting down.

Please note although this description may suggest a straightforward programme of improvement by the patient it was far from it.

The patient made slow progress only to be repeatedly affected by external stimuli (this patient suffered from severe hyperacusis) or by contracting an infection etc. Even as their health improved setbacks were frequent: on occasions they reached the stage where they were able to stand only to have an adverse reaction to an external stimulus - for example a chain saw being used in a neighbouring garden - and they would be back to the stage of coping with only gentle passive exercises for approximately 2 months. Such setbacks were, sadly, all too frequent. However, this was where muscle memory came to the fore: doing the passive exercises seemed to remind the muscles how to work again.

Many features differentiate this physiotherapy package from the type of 'graded exercise' programme which has harmed so many ME patients. The physiotherapy was entirely passive and gentle at the start. It did not look for quick success, it was flexible in its delivery - always working around the needs of the patient on the day and was scheduled for a time of day when the patient felt at their best. When experiencing a deterioration or in a relapse (due to noise exposure or having an infection, for example) the patient never 'pushed through' nor were they encouraged to do so. The neurophysiotherapist was willing to work with the patient they found in front of them on the day, who might be presenting very differently to the same patient they left two days earlier.

This physiotherapy was done patiently, over a number of years. It is the patient's view that over the course of time it made an enormous difference to their quality of life. Had the patient not had the physiotherapy it is likely the contractures of the Achilles tendon would have led to the feet calcifying, meaning the patient would have been unable to walk again. The patient only wishes that they could have had such expert neurophysiotherapy at an earlier stage in their illness.