Dr. Wendy Anderson, one of the patrons of ASAMS and Arachnoiditis Trust, has sent me the results of a two-part study of Arachnoiditis, on which she and Dr. Les Simpson have collaborated and recently written a paper.

In the first part, a comparative symptom study was performed. This looked at the results of Long's US study, my own 1999 International study and a New Zealand study done in 1998.

Symptoms such a tiredness, sensory changes, muscle disturbances were all within similar percentages in the New Zealand (NZ) study to those in the 1999 study and that of Long.

It was noted in the discussion section of the paper, that "Flare up" was a term used

"when manifestations of a systemic, flu-like illness occur. The onset may be immediate or delayed by up to 24-36 hours, and it may take from a few hours to several weeks to settle."

A more detailed examination of the various types of pain, their sites and triggers, was outlined in the NZ study than in the 1999 survey.

Types of pain: sharp pain was experienced by 50% of the 69 respondents;

- dull 64%,
- burning 61%,
- stabbing 44%,
- electric shock 39%.

Pain was also denoted as

- constant (84%)
- or intermittent (58%).

20 of the 69 respondents in the NZ study described some 15 additional types of pain, which included hypersensitivity to light touch, sensation of walking on broken glass, stinging sensation and gripping pain.

As to site:

- 83% had back pain whilst
- 85% had leg, knee and ankle pain and
- 53% had pain in the feet/toes.

Other common sites included the neck (30%) and head/face (29%). 5 respondents (8%) described "whole body", generalised pain.

Some 59% of the respondents complained of headaches and 55% of poor concentration.

66 of the respondents described factors which precipitated or aggravated pain:

these included activity: 90% (c.f. 94% in Long's study);

prolonged sitting/standing around 40%.

Weather and ambient temperature affected 23%.

In terms of the success of different types of treatment:

- 12% found that no treatment helped.
- 24% found relief solely from drug treatment, whilst
- 44% improved with drug and ?other treatment'
- (by contrast, of those using ?other treatment' but no drugs only 20% had relief.)
- 68% of the respondents were using drugs (58% narcotic; 15% anti-inflammatory;
- 11% anticonvulsant;
- 18% antidepressant;
- 17% muscle relaxant).

A variety of other measures were being used by the respondents to reduce their pain: rest, warmth, massage, TENS, acupuncture, relaxation/self hypnosis, frequent position changes etc.

In Part 2 of the study, 46 of the original 69 respondents participated in assessing the value of Evening Primrose Oil (EPO) as a dietary supplement for relief of symptoms experienced by arachnoiditis sufferers.

33 respondents trialled EPO but only 19 were taking the supplement at the end of the study.

This was due to 6 discontinuing due to unacceptable side effects (predominantly gastrointestinal e.g. nausea/vomiting, diarrhoea, acid reflux, abdominal distension, with also one case of weight gain and one of facial swelling).

A further 5 respondents felt that they gained no benefit and had therefore stopped taking EPO.

15 of the respondents tried 2 different products: of which 9 found one to be distinctly superior.

However, the paper states that

"No particular product appeared to stand out as superior to others. The effectiveness of any product appeared to be an individual response."

Dosage ranged from 1,000 to 5,000mg (4,000 being the recommended dose.)

Positive experiences with EPO included:

Improved energy (12 subjects)

Improvement in pain (slight to considerable in 12)

Reduced muscle disturbances, particularly morning stiffness (10)

Headaches reduced (6)

Subjects also reported: greater alertness, better quality of sleep, general improvement of wellbeing.

Red cell shape: Dr. Simpson has performed analysis of the shape of red blood cells, based on his previous work on patients suffering from ME or fibromyalgia.

He has found that, as in those other conditions, there is an increase in the number of flat red cells (normally they are biconcave discs).

This phenomenon has considerable bearing on symptoms such as fatigue, as the flat cells have a reduced oxygen-carrying capacity and thus the increased need for energy in muscles during

exercise is not met and the individual will fatigue much quicker than a healthy individual.

EPO

The use of Evening Primrose Oil to counteract these symptoms is based on studies which have demonstrated that EPO induces improvement in blood flow and oxygen delivery to tissues, including nerve tissues in diabetic individuals (studied in rats): thus preventing or improving nerve conduction deficits.

There will also be a benefit in the blood supply to muscles, which could impact on fatigue as well as muscle disturbances such as spasm.

As the Simpson paper states:

"There is strong anecdotal evidence for the effectiveness of EPO in relieving the symptoms experienced in many chronic conditions where such symptoms appear to be related to oxygen deprivation."

In addition, there has been a Japanese study which used lipoprostaglandin (Lipo PGE-1) to treat the pain of spinal stenosis and was shown to increase blood flow to the affected nerve roots and cauda equina, for a limited period.

EPO is converted in the body to Prostaglandin E-1, so it is reasonable to expect a similar effect. Indeed, PGE-1 has been shown to benefit patients with Raynaud's phenomenon, where spasm of the small blood vessels in the extremities results in poor circulation.

PGE-1 has also been shown to have a beneficial effect on red cell deformability. This brings us back to the abnormalities of red blood cells, observed by Dr. Simpson.

The paper concluded that a recommended daily dose of Evening primrose oil of 4,000mg (4g) may exert a beneficial effect and improve some of the diverse symptoms of arachnoiditis.

However, further research is needed into this and many other aspects of a condition which has no specific pattern of presentation, and may indeed be labelled as one of the similar conditions: MS, ME, FM (fibromyalgia) or Lupus.

The authors also mentioned that the factors* predisposing to the condition and statistics on the prevalence of the condition remain unknown at this time.

(* NOTE: these are biological factors within the individual, which, when the body is challenged by extraneous risk factors such as trauma or chemical insult, interact to result in this incurable condition.

Recognition of these factors might help to determine who in the population is at greater than average risk of developing arachnoiditis from a procedure such as surgery/epidural injection.

These factors may be genetic, biochemical or mechanical, and may involve an autoimmune component)

As the authors state:

"Ideally every person with disabling arachnoiditis should be referred to a spinal unit for inpatient rehabilitation, aiming for maximum function through pain management, occupational therapy and physiotherapy etc., followed by regular monitoring."

Use of EPO or any other dietary supplement should be viewed as part of a holistic approach to treating arachnoiditis, which is a complex condition which is likely to respond best to a range of therapeutic interventions including pain relief, physical treatments, lifestyle changes, psychological techniques and participation in support groups.

Dr Sarah Andreae Jones 2000