There is no doubt in my mind that the way forward brings with it,

ipso facto, a forward-looking approach.

To date, I contend that arachnoiditis sufferers have yet to be provided with adequate resources to manage this incurable condition.

In the past, I have spent some considerable time working on aetiological aspects of arachnoiditis. As most people who know anything about arachnoiditis will be aware, the majority of cases nowadays result from iatrogenic causes: i.e. the condition is caused primarily by medical procedures.

This has unfortunately led to an atmosphere of blame and recrimination and has substantially undermined the doctor-patient relationship. What should be a therapeutic alliance has instead become a hotbed of suspicion and mistrust on both sides.

As I have stated many times in the past, arachnoiditis is a condition which remains poorly recognised and significantly under-diagnosed, so that the true incidence has yet to be ascertained.

This is a result of a vicious circle: the condition is perceived as rare so is considered as a possible diagnosis only after more common conditions have been excluded, or, as in many cases, diagnosed instead of arachnoiditis.

Hence we see many people diagnosed with Failed Back Surgery Syndrome or epidural fibrosis. These are somewhat vague terms that fail to convey the full clinical picture.

Furthermore, as arachnoiditis mimics other conditions there may be a diagnosis of Multiple Sclerosis, fibromyalgia, or lupus-type syndrome.

More seriously, some patients will be told that tests have failed to demonstrate any organic cause for their multiple symptomatology.

Often the clinician (despite no formal training in psychiatry) will adjudge the patient to have a psychological problem; naturally, any quite understandable emotional reaction to the chronic debility caused by arachnoiditis is deemed to support this diagnosis.

Worse still there may be actual or implied accusation of malingering, especially if there is litigation involved.

Failure to fully grasp the scope of the condition and the level of pain involved, added to reluctance to use narcotic medication for fear of professional or legal censure may lead the doctor to attribute the patient's request for increasing doses of medication to an addictive problem.

Due to the iatrogenic nature of the condition, there may well be a reluctance to openly diagnose arachnoiditis, for fear of legal reprisal. This contributes significantly to the vicious circle.

Therefore, I contend that the prime factor in under-treatment of arachnoiditis is that the condition is poorly recognised: even when diagnosed, the full clinical extent is often underestimated.

The second major factor in less than optimal treatment for arachnoiditis is inadequate pain relief.

In my article "The Scourge of Unrelieved Chronic Pain", I explored the reasons behind this state of affairs and quoted several eminent specialists in the fields of Palliative Care

and Pain Management.

It is now coming to light that a significant number of pain sufferers fail to be allowed access to adequate pain relief. Prejudice and lack of awareness of accurate information have combined to cause a reluctance to prescribe narcotic analgesia.

Moreover, often the degree of psychological distress is overstated by clinicians and too great an emphasis placed on measures to tackle this aspect of the condition.

Frequently, patients are enrolled on an intensive "Pain Management Course", for four to six weeks, after which they are deemed to be capable of self-management.

Naturally, this brings with it an in-built criticism of those who either fail to gain benefit from the course or who ?fall by the wayside' and are unable to maintain a rigorous enough psychological regime to cope with the unremitting pain.

Whilst it has been a mainstay of the Pain Management strategy to state that pain itself does no harm, experts such as Forrest Tenant are now realising that this is far from true; in fact, unrelieved chronic pain can lead to a whole gamut of physical problems in addition to the expected psychological ones.

These are generally related to the chronic over-production of adrenaline, insulin and cortisol. Recognition of the effects of these substances would enable clinicians to approach pain far more proactively.

An ongoing, incurable condition such as arachnoiditis requires ongoing, continuous management.

It would be inconceivable for a Rheumatologist to fail to treat a patient with Ankylosing Spondylitis on an ongoing basis.

It is therefore incumbent upon doctors dealing with patients with Arachnoiditis to treat the condition on an ongoing basis, and any regulatory barriers to pain management should be removed.

In the United States, Intractable Pain Treatment Acts (ITPAs) have been adopted in several states. However, some ITPAs may actually hinder patient care as the use of narcotic analgesia is defined as a last resort therapy.

The WHO guidelines comprehensively cover government regulation of both opioid analgesics and health professionals, and aim to ensure availability of narcotic analgesia where appropriate while preventing diversion to non-medical (and thus illegal) use.

However, at the end of the day, it is down to the individual clinician to assess the needs of his/her patient and act accordingly to prescribe sufficient analgesia: this requires

(a) trust that the patient has a genuine need

(b) clinical judgement to support the recognition of this need and

(c) freedom from anxiety as to possible legal or professional consequences.

Before I embark upon my suggestions for a way forward in management of arachnoiditis, I would like to include a quote from the recent film "The Insider" which deals with someone "whistleblowing" on the tobacco industry.

Whilst the background to the quote is somewhat different from my usage of it, I feel it nevertheless conveys an important message (and note that quite a large proportion of arachnoiditis patients are in their 30s and 40s so they may have young families):

"In combat, events have a duration of seconds, sometimes minutes; what you're going through goes on day in, day out, whether you're ready for it or not; week in, week out, month after month after month; whether you're up or whether you're down.

You're assaulted psychologically, you're assaulted financially, which is it's own special kind of violence because it's directed at your kids: what school can you afford, how will it affect their lives? You're asking yourself, ?will that limit what they become?' You feel your whole family's future's compromised, held hostage..."

A further vital point must be made: arachnoiditis remains an incurable condition at this time. This means that the adage "Prevention is better than cure" does not apply. Hence the urgent need to prevent those cases which are preventable.

Three-pronged attack on Arachnoiditis

1. RECOGNITION OF CASES OF ARACHNOIDITIS

2. PROACTIVE APPROACH TO TREATING ARACHNOIDITIS

3. PREVENTION OF FURTHER PREVENTABLE CASES

RECOGNITION

As I have explained, all too often patients are unable to get a diagnosis. Basically, I believe that the diagnosis should be based upon clinical assessment rather than upon results of imaging tests such as MRI scans, which are limited in their ability to pick up early cases and indeed, may result in false negatives at any stage of the condition.

As with any clinical assessment, the first level is taking an accurate and complete history. Clinicians need to be vigilant for red flags that may be pointers to the possibility of arachnoiditis:

A history of any of the following procedures should raise the index of suspicion: myelogram, epidural steroid injection, epidural anaesthesia, spinal surgery, repeated lumbar punctures (especially if there is a bloody tap).

In addition, further historical pointers include meningitis (infective or chemical), spinal injury or longstanding mechanical spinal problems such as degenerative disc disease or stenosis.

In taking a history on the pain: its distribution may not conform to anatomic areas (which tends to lead the clinician to suspect the veracity of the patient's story) however, if the pain is chronic (more than 6 months' standing) then there may well be an element of central pain.

This can account for non-anatomic distribution, bizarre sensations and pain in numb areas (pathognomonic of neurogenic pain).

Examination generally fails to show a typical clinical presentation. Waddell's signs are not necessarily indicative of malingering; for instance, superficial tenderness can be accounted for by allodynia.

Other tests commonly employed to identify the malingerer include Hoover's test, which may be confounded by bilateral weakness, or Burn's test which may be impossible for the patient to perform due to secondary musculoskeletal effects that contribute to (and in turn are caused by) altered spinal dynamics.

As already discussed, tests may fail to disclose the cause or indeed, the extent of the patient's condition. It is well recognised that MRI findings tend not to correlate well with clinical problems, and in any case, an MRI cannot show pain any more than a chest X-ray can show arrhythmia.

In addition, it is vital that clinicians be made aware of the syndromic nature of full-blown arachnoiditis. Whilst many of the symptoms arise secondarily, generally through under-treatment of pain, nevertheless, the clinician must be prepared to address symptoms such as headaches, excessive sweating and poor circulation as a part of the syndrome.

To this end, I would like to see a programme of education initiated: aimed predominantly at primary care physicians, who are, so to speak, on the frontline. In the UK, the Arachnoiditis Support Groups (ASG) had produced handbooks for this purpose.

However, distribution to all GPs is an impossible feat for a low-profile charity dependent on volunteers to run it and small donations from members.

I would therefore like to see Government action to assist this endeavour.

PROACTIVE MANAGEMENT:

This requires a multimodal approach.

"It has now been established that the treatment for chronic pain and disability, in order to have any chance of success, must be:

MULTIDISCIPLINARY, INTENSE AND PROLONGED." (1)

As Katz wrote in 1998(2):

"Patients' needs include freedom from adverse (especially drug) reactions, improvement or maintenance of ability to perform activities of daily living (ADL), and a satisfactory quality of life."

Amongst the principles of pain management, most vitally, respect for the patient, knowing when to treat pain, treating early and aggressively, addressing psychological aspects and employing a multidisciplinary approach.

Therapeutic modalities that might be effective in arachnoiditis include:

Of prime importance: Pharmacological modalities: narcotic analgesics and adjuvant medication (antidepressants and anticonvulsants)

Physical modalities: including gentle exercise (e.g. hydrotherapy) massage, electrical counterstimulation

Lifestyle measures: such as encouraging patient to stop smoking; adopting pacing measures; this may also include implementing supportive measures such as disability aids, financial help.

Psychological modalities: supportive and informative as well as hypnosis, relaxation training etc. It is also important to involve close relatives.

This is merely a brief, truncated overview of a highly complex approach, which should be implemented on an individual basis.

PREVENTION OF PREVENTABLE CASES

As I have already stated, the majority of arachnoiditis cases nowadays arise from iatrogenic causes.

MRI scanning techniques have largely superceded use of myelogram dyes. Certainly, oil-based dyes are no longer in use and the water-based dyes used are less toxic than ones previously

utilised.

Spinal surgery may lead to localised arachnoiditis lesions. However, surgery is not generally undertaken if there are other options available.

Use of chemotherapeutic agents such as methotrexate intrathecally can cause arachnoiditis, but these drugs are only used in severely ill patients for whom the treatment might mean the difference between life and death.

Epidural anaesthetics may cause arachnoiditis in a small minority of patients. However, it would be impractical to ban this technique. For clinicians to assess the true level of risk remains impossible as we do not know the extent of risk, no long-term studies being available.

It would, however, seem prudent to assess young women with a history of pre-existing back problems as being at potentially higher risk, it being recognised that spinal abnormalities confer a greater chance of adverse events.

The main thrust of prevention must rest on epidural steroid injections. (ESIs)

Since the 1980s, experts such as Dr. Dewey Nelson have been speaking out about the risk of arachnoiditis due to epidural steroid injections. Dr. Charles Burton of the Institute of Low Back and Neck Care in Minnesota has written extensively about Depo-Medrol, a steroid preparation that contains neurotoxic preservatives.

Indeed, earlier this year, a New Jersey court found for a plaintiff who was awarded $12 million because she has arachnoiditis due to an intrathecal Depo-Medrol injection.

I have written extensively on this topic elsewhere, so will not reiterate the bulk of the argument. However, in brief:

The benefit: risk ratio is not commensurate with continued use of this procedure.

A number of studies have found ESIs to be ineffective both in acute and chronic conditions. The AHCPR Clinical Guidelines from 1994 (Acute Low Back Problems In Adults) found that

"There is no evidence to support the use of invasive epidural injection of steroids, local anaesthetics and/or opioids as a treatment for low back pain without radiculopathy."

The Australian NHRMC report suggested that ESIs are of greater use in sciatica when there is a substantial inflammatory component.

More recently, McQuay (3) has cited a NNT of 7.3 for greater than 75% pain relief in the short-term and 13 for more than 50% relief in the long term. Compare this to NNTs of between 2 and 3 for adjuvant analgesics such as antidepressants and anticonvulsants for intractable neuropathic pain: ESIs are patently much less effective.

Indeed, the Cochrane Review from 1999 (4) concluded "Convincing evidence is lacking on the effects of injection therapies for low back pain."

As to risk, this has yet to be fully quantified, due to lack of recognition of cases, therefore under-reporting of ADRs (adverse drug reactions). There is a dearth of long-term studies that might pick up arachnoiditis as an ADR.

Currently, the UK Department of Health is running a study on ESIs, which is expected to be reported on in 2003.

Nevertheless, there are numerous papers reporting cases of adverse events.

Whilst it has been believed by the majority that the neurotoxic preservatives in most steroid preparations are only harmful if placed intrathecally, it must be remembered that around 10% of substances placed epidurally may reach the subarachnoid space, hence epidural doses of opioids or anaesthetic agents are known to be 10 times that of intrathecal doses.

In addition, there is the risk of dural puncture, which the NHMRC report quoted as on average "at least 5%". This would lead to injection of the steroid preparation directly into the subarachnoid space.

Furthermore: ESIs are not licensed for use around the spine and the manufacturers state that they do not recommend this use.

In New Zealand, use of ESIs is deemed to be "experimental" and specific written informed consent must be obtained from the patient. In the UK, unlicensed or experimental use remains a legal option for medical practitioners, which calls into question the point of having a licensing authority in the first place.

In any case, how can a patient give informed consent if the doctor about to perform the procedure is not himself informed? Again, we are looking at a need for education.

My case is that use of ESIs should be discontinued on the basis that the benefit: risk ratio is such that potential benefits (small and short-lived) are significantly outweighed by the risks (unquantified as yet, but permanent damage may occur).

This is the only way in which to prevent cases of arachnoiditis secondary to ESIs, which, in my view, are wholly preventable.

SUMMARY

I am hopeful that both arachnoiditis sufferers and the members of the medical profession under

whose care they reside, will be able to look forward into the new millenium instead of persistently looking backward over their shoulders at the unfortunate tangle of recrimination and attempted redress that has been the situation thus far.

In this forward looking approach, I fervently hope that doctors and patients can forge a strong therapeutic alliance to combat a condition which remains relentless in its effects on the lives of its victims.

Only once we have achieved this, can we look further into ways of halting the condition.

Dr. Sarah Andreae-Jones MB BS

Patron of ASG

November 2000.

1 Kelly Patrick Flannigan MD, FRCP (C) 1995 from Pain is a Blind Guide In Injury Management)

2 Katz WA Am, J Med 1998; 105:2S-7S The Needs of a Patient in Pain

3 McQuay HJ Internet resource : Epidural corticosteroids for low back pain

http://www.jr2.ox.ac.uk/Bandolier/painres/painpag/Cronrev/Other/CP076.html

4 Nelemans PJ, Bie RA de, Vet HCW de, Sturmans F Injection Therapy for subacute and chronic benign low back pain (Cochrane Review) In: The Cochrane Library, Issue 4, 1999.

Oxford: Update Software