

## ADHESIVE ARACHNOIDITIS

"Quaeras de dubiis, legem bene discere si vis"

(Inquire into them, that's how to know what things are really true.)

### THE CONDITION:

Arachnoiditis - a name to conjure with. To those who've never heard of it before, it invariably brings to mind 'something to do with spiders'.

In fact, the term is simply medical jargon for inflammation of the arachnoid or middle layer of the meninges, the three membranes that surround the brain and spinal cord.

It is called 'arachnoid' because it resembles a spider's web in appearance.

To those who know the term because it affects their daily lives, it conjures up interminable pain, invisible disability and an uncertain future. This illness damages not only the body, but also self-confidence, relationships and families.

So what is this mystery illness? Adhesive arachnoiditis is the most severe form of arachnoiditis, which leads to a variety of symptoms. It is mainly a spinal condition, but that only tells a small

part of the story.

It has been likened to, and mistaken for, fibromyalgia, chronic fatigue syndrome, failed back surgery syndrome and ME.

In truth, it is actually more similar to Multiple Sclerosis and spinal cord injury, because it is a condition affecting nerves rather than simply being a 'back problem'.

However, because it tends to afflict those who are 'back sufferers', it has gained a reputation as being about 'bad backs'.

In fact, adhesive arachnoiditis is unlike any of these other conditions, in one vital respect: the majority of cases are caused by invasive medical procedures such as myelograms and injections around the spine (epidurals, spinals etc.) Other causes include meningitis.

Adhesive arachnoiditis is essentially like chronic meningitis, affecting the nerve roots that exit from the spinal cord. It involves a chronic inflammation leading to scar tissue that binds nerve roots together and sticks them to the outer layer of the meninges, the dura.

These nerve roots carry information to and from various areas of the body - information about sensation and messages about movement. In adhesive arachnoiditis, instead of running freely, they resemble overcooked spaghetti, all matted together and squashed.

It is not hard to see why this effectively scrambles the messages carried in these nerves. Incoming sensations are distorted and become excruciating pain and bizarre sensations; outgoing messages cause bursts of muscular activity- painful spasms and cramps. Various other aspects of the body's functions are also affected.

Adhesive arachnoiditis cannot be cured, and palliative treatment of the nerve pains requires high doses of various strong medications including narcotics. Whilst not a terminal illness, this

condition diminishes the sufferer's quality of life for the rest of their lives.

The late Dr. Bourne wrote:

"The relentless and progressive pain syndrome of arachnoiditis is taxing to the patient's morale. In many instances doctors, relatives and friends fail to realise that the pain can be as bad as terminal cancer, without the prospect of death to end the suffering."

#### CAUSES:

For the most part these days, chemical insult in the form of injections into the spinal fluid is the causative factor, although the majority of cases involve a number of different factors.

For example, someone with a 'back problem', in the mid to latter part of the Twentieth Century may well have undergone a myelogram test to find out what was wrong, spinal surgery attempting to treat (possibly repeated surgery), and when treatment failed to provide relief, a series of epidural injections.

All of these invasive treatments could be contributory to arachnoiditis. Toxic chemicals, from myelogram dyes (rarely used since MRI scans became available), the preservatives in epidural steroid injections and epidural or spinal anaesthetics, chemotherapy for leukaemia and baclofen pumps for children with cerebral palsy all carry a potential risk of causing this bodily reaction.

The area into which they are injected is highly sensitive and it may be that some people are more prone to a strong reaction than others. Until further research is carried out, we cannot be sure who is at greater than average risk.

Arachnoiditis cannot be relegated to the pages of history simply because oil-based myelogram dyes are no longer in use.

Instead, it is imperative that we acknowledge the "clear and present danger" occasioned by current medical practice, in particular chemical insult to the subarachnoid space from intraspinal chemotherapy of various types.

As Burton points out, the subarachnoid space is used to this day as a medical highway, a route for the delivery of a variety of chemicals directly into the cerebrospinal fluid, where they can potentially bathe the entire cerebrospinal axis.

As Oldberg warned in 1940 in his paper,

"A Plea for respect for the tissues of the Central Nervous System" ( ),

this is not without danger, though patients and sometimes even the administering doctors, are unaware of the risks that are being run.

More recently, Burton reiterated these warnings in his 1999 paper, "The Subarachnoid Space: 'Salum sanctorum' or Toxic Dump" ( ).

The emphasis in these two papers has shifted from oil-based myelogram dyes in the first to the ongoing dangers of current invasive procedures such as intrathecal catheters for drug infusion.

Burton states:

"The adverse sequelae relating to the introduction of foreign body substances into the body's 'salum sanctorum' remains a game of chance for the patient."

Due to a sometimes prolonged delay between exposure to the causative factor and onset of symptoms, the link is often not recognised. Hence we have as yet no way of knowing the

magnitude of risk for various medical interventions. This is an important area of future research.

#### THE SITUATION AT PRESENT:

Some amongst the medical community remain sceptical about arachnoiditis.

In 2000, in a paper entitled: "Symptomatic lumbar spinal arachnoiditis: fact or fallacy?" ( ),

Petty remarked:

"These patients place a heavy diagnostic and therapeutic burden on the treating practitioner"

with a concluding comment:

"...the diagnosis of 'clinical arachnoiditis' is essentially a diagnosis of despair or a justification for otherwise unsustainable litigation."

Diagnosed or not, patients' suffering continues relentlessly.

Despair is not solely the preserve of those who are diagnosed, indeed, it is far more prevalent in those who have no diagnosis, and is often accompanied by fear, anger and bewilderment, none of which is advantageous in encouraging patients to come to terms with their illness.

Those afflicted with arachnoiditis understandably often feel that they are being 'stonewalled'

which inevitably leads to distrust and anger.

In 1997, Congressman James Traficant submitted a Bill to the U. S. Congress( ) calling for a ban on myelogram dyes, and research into myelogram-related arachnoiditis and potential treatments.

Traficant pointed out:

"A large number of medical professionals do not know how to diagnose myelogram-related arachnoiditis...lack of information prevents the physician from recognizing the disease."

Expert Dr. Charles Burton, of the Institute of Low Back and Neck Care, Minnesota, has written extensively about arachnoiditis, and has called the condition a 'scientific orphan'.

In his Burton Report of June 2000 ( ), he stated:

"There exists no area of medicine today where greater, or more cruel suffering has been produced...than that causally related to adhesive Arachnoiditis... this disease entity remains essentially unknown, unreported and unrecognised."

The recent New Zealand Ministry of Health Report on arachnoiditis ( ), identified the limited number of experts in this field, and the lack of coherent research being conducted, which the author, Peter Day, and his associates suggest may be a considerable hindrance to future work on this condition.

Whilst commending the involvement of various support groups, citing them as a useful resource and

"an important impetus to future research";

the authors acknowledge that

"it is not clear how co-ordinated and systematic research into arachnoiditis will proceed."

As yet, we don't know the full scale of the problem, although the thousands of cases that are known are clearly the tip of the iceberg.

The 2001 New Zealand stated:

"It was not possible to calculate the actual population-based incidence or prevalence of arachnoiditis in any form as the clinical data was not available."

Addressing this lack of information is a vital aspect of future research.

#### THE WAY FORWARD:

Instead of ignoring history, which will lead to repetition of past errors, we must learn from it.

A good first step would be for the United Kingdom and the United States to emulate New Zealand and commission reports on arachnoiditis.

As Burton remarks in his Supplementary Observations on the report( ):

"The literature review...should have been done a long time ago by Health agencies in the United States or England".

Secondly, we need to establish research into arachnoiditis to ascertain the extent of the problem, and to better understand aspects of the condition such as a possible link with autoimmune conditions.

The latter may enable us to work towards curative treatment, which is currently unavailable, and improve palliative treatment.

Thirdly, we need to look at prevention. Nowhere is the old adage,

"Prevention is better than cure"

more apposite, because there is, as yet, no cure.

The New Zealand report's closing recommendation serves as a timely reminder:

"Prevention will be an important aspect of health strategies to address this condition given the recognised aetiology...particularly the prevention of post-operative and post-injection complications."

In summary, we need a 3-pronged attack on arachnoiditis:

1. Recognition of cases, leading to statistics on prevalence.
2. Proactive approach to treatment
3. Prevention of further preventable cases.

In order to achieve these aims we need:



## Education and Research

We also need to remember Dr. Bourne's words:

"Compassion is an important consequence of comprehension of the existence and nature of arachnoiditis." and those of William Shakespeare:

"He jests at scars who never felt a wound"

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