

2010 ARACHNOIDITIS SURVEY RESULTS

QUESTIONNAIRE 1

Total number of respondents: 151, of which 33 had taken part in previous survey(s).

Gender: Ratio of female to male was 3:1 (75% female, 25% male)

Age: no under 18s, only 2 under the age of 30. 65% were between ages 45 and 60. 4 over 75s
Diagnosis:

80% of respondents had an established diagnosis of arachnoiditis, 20% did not. However, only 52% had a specific diagnosis for their chronic pain, and 48% did not.

37% also had a diagnosis of chronic pain syndrome. Other physical diagnoses included: Fibromyalgia/myofascial pain (30%), Peripheral Neuropathy (25%), Complex Regional Pain Syndrome (10%), Multiple Sclerosis (5%), Autoimmune conditions (6%), Arthritis (27%), Chronic fatigue (13%), Central pain (9%). Failed Back Surgery Syndrome (5 cases) epidural fibrosis (1 case); Autonomic neuropathy (1 case); cancer (1 case); hemiplegic migraine (1 case); status migrainus (1 case); central sensitivity syndrome (1 case);

Many respondents had multiple diagnoses e.g. Chronic pain syndrome, Peripheral neuropathy and arthritis.

15% had been told their symptoms were due to psychological causes, 26% had no diagnosis to

explain their symptoms and 13% had been told they did not have arachnoiditis. 1 person was told they were 'drug seeking', another that back pain was due to depression.

70% had a diagnosis of arachnoiditis from an MRI scan, 26% were diagnosed with a myelogram, 16% had CT scan and 20% were diagnosed solely on clinical history and examination. Other avenues of diagnosis included surgery. One case had multiple investigations: Bone Scan, Fibrinolytic Studies, Thermography, Gamma Ray Radio Active Isotope, CT scan, EEG. Another case had nerve conduction studies.

50% of diagnoses were made by neurosurgeons, 29% by radiologists, 17% by orthopaedic surgeon, 16% by neurologists, 7% by general practitioner, 4.5% by rheumatologist and nearly 5% by psychologist/psychiatrist. Other professionals included: pain management specialists/physiatrist, anaesthetist.

Onset of symptoms:

30% of respondents had symptoms lasting 10-20 years, with a further 25% having had symptoms for over 20 years. Less than 3% had had symptoms for less than a year, 21% 1-5 years and 20% 5-10 years.

So 55% of respondents had had symptoms for more than 10 years, 75% for more than 5 years. Therefore the survey is looking mostly at longstanding cases.

In contrast, , 26% had been diagnosed with arachnoiditis for 5-10 years, 26% 1-5 years, 17% less than 1 year, 14.5% had had a diagnosis 10-20 years and 5.5% over 20 years, whereas 32% had a diagnosis of chronic pain for 10-20 years, 22% 1-5 years, 16% 5-10 years, 14% over 20 years, 6% less than one year.

The length of time between onset of symptoms and diagnosis of arachnoiditis was 1-5 years in 31%, 5-10 years in 22%, less than one year in 20% and more than 10 years in 27% (of which 10% more than 20 years).

In other words, nearly 50% of people with arachnoiditis had to wait more than 5 years from onset of symptoms to get a diagnosis. Over 80% don't get diagnosed until a year after the onset of symptoms.

Areas affected by arachnoiditis:

90% of cases had lumbar spine involvement, 59% sacral. Thoracic arachnoiditis affected 35% and cervical 29%. 7.5% had cranial involvement.

41% had involvement of several levels, but within one spinal region (e.g. lumbar). 24% had involvement in several regions. 11% had arachnoiditis at only one spinal level. 18% did not know how much of the spine was affected. 77% reported that the extent of the condition had been confirmed with scans.

Complications:

Tarlov cysts*: 15% (* an associated condition but not necessarily a complication)

Arachnoid cyst: 12%

Arachnoiditis ossificans: 11%

Syringomyelia: 8%

Hydrocephalus: 3%

28% had not been told of any complications and a further 17.5% reported no known complications

30% 'other' included: neurogenic bladder/bowel; Horner's syndrome; pseudomeningocele (4 cases); Cauda Equina Syndrome (7 cases); Thoracic pseudocysts; autonomic dysfunction; spinal lipoma

Procedures/events:

The majority of respondents reported several factors/events. Most had undergone surgery, had also had myelogram(s) and epidural steroid injections. Some had also had other injections,

such as nerve blocks/facet joint injections, presumably in a bid to manage their pain.

Spinal surgery: 79%

Epidural steroid: 70% Depo-medrol/depomedrone 5 cases

Lidocaine+ cortisone; Triamcinolone + Procaine; 'steroid with preservative' ,
Marcaine + Clestone;

Many had a number of ESIs (one case had 13)

Myelogram: 60% Oil-based (Myodil/Pantopaque/Ethiodan) 11 cases; (including 1 lipiodol)

Water-based (e.g. Metrizamide, Isovue 300, Omnipaque etc.) 5 cases

A number had had multiple myelograms

Epidural anaesthetic: 49%

Facet joint injections: 46%

Nerve root blocks: 45%

Lumbar puncture: 41%

Spinal trauma: 36%

Radiculogram/epidurogram: 24%

Congenital spinal problem: 16%

Also other events: a case with 2 brain tumours and a brain cyst in childhood, requiring multiple operations including a shunt.

One especially complex case: Spina Bifida (repaired), Tethered Cord (repaired 2x), scoliosis, pseudomeningocele, bulging disks C6, and multiple lumbar + S1, syringomelia, Chiari (also had Hypothyroidism)

Epidural blood patch (one case had 3 patches);

1 case specified spinal rather than epidural anaesthetic.

1 case of intrathecal chemotherapy for lymphoma (also had epidural anaesthetic in labour)

Discogram at multiple levels

Spinal stenosis : 3 cases

3 Respondents mentioned Gadolinium contrast used in MRI, causing a reaction

Infections:

7% had had meningitis (8 cases), 1 case of encephalitis. 4 cases of epidural abscess. 1 case of Tuberculosis.

There was also a case of aseptic meningitis. 1 case of severe staphylococcal infection (? Site) and one of lumbar abscess (superficial).

Belief about cause of arachnoiditis

57% believed surgery was the cause of their arachnoiditis. 40% epidural steroid injection, 35.5% myelogram, 20% epidural anaesthetic, 20% spinal trauma, 12% facet joint injection, 12% nerve block, 10% congenital spinal problems, 9% lumbar puncture, 5% infections.

Progression

78% of respondents felt that arachnoiditis is progressive, 21% did not know and less than 1% felt that it does not progress.

Most respondents described their own experiences of increasing symptoms over years.

One respondent wrote: "Everything I've read or researched leads one to believe that there is the possibility of progressive issues. However, not everyone is affected and thankfully so."

Support Groups.

27% reported that they belong to local/national support groups, whereas 76% said they belonged to an online group. Amongst the groups represented: COFWA, Life with Arachnoiditis, Arach_Friends, Tarlov-aracEuropeInformation, The A Word, Arachnoiditis Connection.

Countries:

52% North America

20% UK
7.5% Canada
7% Europe (including Scandinavia)
5% Australia
2.5% Africa (3 cases)
1 case India and 1 Middle East

Many thanks for the time and effort given by those who contributed and of course to Kim Nevitt for her invaluable work.

Part 2 will look at how arachnoiditis affects peoples' lives. It is a rather lengthy, detailed questionnaire, but the aim is to give people the opportunity to document the complexities of living with arachnoiditis.

To date we have around 50 responses: once we have at least 100 we will be able to collate and publish some useful results.

Part 3 will look at treatments people have tried. Hopefully this will give us useful insights into what has been effective and what hasn't.

Once we have collated results from all the parts, a report will be written to discuss the findings of the survey and highlight areas of interest.