

Christine Hopkins, a New Zealand nurse, wrote a thesis in 1998 on

"The Presenting symptoms associated with arachnoiditis and the experience of living with them in everyday life".

In this study, she interviewed in considerable depth, 11 participants, 1 of whom had no pain.

The others experienced pain in various sites, burning, numb and cold areas, stabbing; flares of pain; constant; sore bones; 'ice burn', deep; cramping; intensifies with activity. 'not like any other sort of pain'. 'a freezing cold burn'. They also had headaches: linked to myelograms and epidural steroid injections.

In addition to their severe physical pain and impairment, the interviewees described the emotional aspects of living with this incurable illness.

"The study findings also indicate the complexity of the situations in which those with arachnoiditis find themselves."

The participants' perceptions of their level of function reflected "a high level of disability linked largely to pain, as an immobilising factor in their lives."

Hopkins also remarked on social isolation as a

"marked feature of participants' lives".

Sufferer Janet Kraal wrote her story, which was published in the book "Released From the Web" in 1997. (Minerva Press).

Janet described the pain of arachnoiditis thus:

"it saps the strength and crowds the consciousness, until the person is overwhelmed and wishes quite simply for the release of death."

She wrote of living with arachnoiditis:

"It's hard to accept a condition which gives pain twenty-four hours a day. It's taxing on you mentally and one becomes exhausted with the pain, trying to do what may be the simplest of tasks.

We are advised to try not to dwell on the pain, not to brood, to concentrate on other things, but when the pain is overwhelming one simply cannot be distracted or think of anything else...We feel trapped and helpless, we feel miserable, tense, angry and irritable."

Dr. Antonio Aldrete noted in his book, "Arachnoiditis, The Silent Epidemic":
"Although symptoms of ARC are not specific, they are very real, and suffering patients bear these every day."

PROGNOSIS

Arachnoiditis has been described as an insidious disease that is incurable. Guyer's paper on the prognosis of arachnoiditis ([\[1\]](#)) suggests that there tends to be a spectrum of the course of the disease, which varies from mild and non-progressive, to a fulminating progression that may cause paralysis and even death.

Wilkinson ([\[2\]](#)) believes that progression after the first 24 months is unlikely to be due to the disease process alone. Most authors state that its onset may be years after the precipitating cause.

The NZHTA Report noted:

"There is a scarcity of literature dealing with the prognosis of arachnoiditis."

The author also remarked that the prognosis was complicated by a variety of factors such as variable onset and spectrum of symptoms and difficulties in diagnosis and management as well as the original underlying spinal pathology.

In general, arachnoiditis presents a highly variable clinical picture, with a fluctuating course of remission and intermittent 'flare-ups'.

Some patients seem to reach a 'plateau' and stabilise without further deterioration, whereas there is a group of patients who develop a relatively rapid deterioration (within a matter of months) during which they tend to lose function in the affected limb(s).

This tends to happen after a seemingly trivial event such as a minor fall or car accident.

Patients with retained oil-based myelogram dye may have either a thin diffuse film or localised encapsulated deposits. The latter may be disrupted by an event such as a minor car accident or a fall.

Hence there may be sudden, seemingly inexplicable onset of symptoms even if there has been substantial interim period since the myelogram procedure (several years).

An alternative explanation might be that trauma (or further surgery) involves blood within the epidural or subarachnoid space and as we have seen, this can act synergistically with a chemical agent present, or can, by itself, be irritant enough to precipitate clinically significant adhesive arachnoiditis.

Whilst Guyer suggests that life span is on average shortened by some 12 years, there is no literature covering a mortality rate from the condition.

Of itself, the disease does not seem to be life-threatening, but a combination of high doses of analgesia and other drugs, prolonged immobility etc. have an undoubtedly deleterious effect on the body as a whole and may thus precipitate further morbidity and possibly mortality.

Furthermore, the ongoing daily onslaught of pain and debility can lead to a severe depression and suicidal actions. A number of sufferers have taken their own lives, unable to live with the extent of the suffering involved.

[1] Guyer DW, Wiltse LL, Eskay ML and Guyer BH. *Spine* 1989 Dec; 14(12): 1332-1341 The long range prognosis of arachnoiditis.

[2] Wilkinson HA Alternative therapies for the Failed Back Syndrome in The Adult Spine, JW Frymoyer ed.1991