

A. Muscle spasms and spasticity: medication such as baclofen may be helpful, but drugs such as diazepam are highly addictive even after a short period of use: this means that an increasing dose will become necessary to achieve a therapeutic effect, and if discontinued, withdrawal symptoms are likely to be experienced in about 50% of patients.

Physical treatments such as massage may help to reduce the discomfort.

Nocturnal spasms may respond to quinine. (Even small amounts such as that found in soft drinks such as tonic water.

B. Incontinence: (urinary and/or bowel): this requires specialist assessment and treatment. There are a number of different measures that can be used to help manage these problems.

These range from simple hygiene measures (adequate fluid intake, use of pads in underwear) through pelvic floor exercises and biofeedback techniques, self-catheterisation (or manual bowel evacuation) to medication (such as oxybutinin) and possibly surgical techniques to strengthen weakened sphincters or pelvic floor muscles.

Cranberry juice may be helpful in reducing the frequency of urinary tract infections; it needs to be in quite large quantities, though, such as at least half a litre a day. Note: it may not be appropriate for some patients: check with your doctor first. Potassium citrate powder helps to reduce the discomfort during an attack of cystitis.

C. Insomnia: this often arises through the increased severity of neurogenic pain at night, which is a typical aspect of this type of pain.

Insomnia is a significant factor in exacerbating the general debility caused by the condition. A proportion of arachnoiditis patients is diagnosed with fibromyalgia, a condition that is recognised as being linked with loss of restful sleep. Muscle spasms are another common cause of disturbed sleep.

It is best to avoid use of hypnotic drugs such as benzodiazepines (temazepam/ ativan etc.) which as previously mentioned are highly addictive within a short period of commencing their use. Antidepressant drugs given in low dose as pain relief are often given at night and their sedative effects are then beneficial rather than adverse effects, as they would be by day.

Again, simple measures the patient can use might include using an electric blanket to ensure warmth, having a bath and/or a warm milky drink prior to retiring may help aid restful sleep.

It is best to avoid use of alcohol, as it is not generally good at promoting restful sleep. Similarly, caffeine should not be taken after 4pm. and reduce nicotine intake if possible.

It may not be realistic to expect to sleep through the night, especially as even healthy people are naturally predisposed, biologically speaking, to benefit more from a short afternoon nap and a relatively short late-night sleep.

Thus building in an afternoon nap may be advantageous, provided it is not too long.

Try not to go to bed before you are sleepy or tired: lying awake "resting" is very tempting when it may seem the only place to get comfortable (and often warm!): but it is best not to do this in bed, rather on a comfortable sofa, for example.

Herbal preparations such as Kalms usually contain valerian and perhaps hops (see below): check with your doctor/ pharmacist before taking these as they may interact with your prescribed medication.

Melatonin is a naturally occurring hormone produced by the pineal gland, which has been studied in Canada and found to be beneficial in promoting sleep. As we age, our natural melatonin levels drop: so once woken at night, it is difficult to fall asleep again.

A dose of 0.3mg restored normal sleep in people over 50; however, some insomniacs needed 10 times that amount, so doctors will need to adjust the dose: in order to achieve a normal blood melatonin level.

Although it was denoted in USA as a supplement, it is really a drug and overdose can lead to adverse effects such as grogginess in the morning. Also, it is important to bear in mind that we do not as yet know enough about the delicate balance of our own naturally produced melatonin and the way in which supplementing it might affect this. For this reason, its use is not advised.

D. Poor circulation: this is a very common problem in arachnoiditis patients (and indeed, in the general population, of which up to 5% may suffer from Raynaud's phenomenon) and is in part due to nerve supply (sympathetic system) and part to lack of mobility.

It is important to adopt common sense measures such as ensuring that the affected body part (usually hands, feet and nose) are kept well wrapped and not exposed to the cold.

If finances allow, it is best to keep the house heated to a constant temperature rather than have one room as a "hot-spot" and the rest of the house cold. Repetitive movements such as typing may worsen the symptoms.

Overheating the affected part may also make matters worse. Avoidance of caffeine and nicotine can be helpful as they both act as vasoconstrictors. Medication includes calcium-channel blockers such as nifedipine and sympathetic nervous system inhibitors such as prazosin.

In November, 1999, the Lancet published the results of a study at St. Bartholomew's Hospital in London, which looked at the use of a topically-applied gel containing nitric oxide, (a chemical produced within the walls of blood vessels) to treat Raynaud's phenomenon.

It was found that this gel tripled the blood flow to patients' fingers, to the extent that it approached that found in untreated healthy volunteers. There were no reports of ill effects.

Fatty acids of the omega-3 type, which are found in fish oil, may help to reduce the vascular spasm that causes Raynaud's, as they induce a more favourable vascular response to cold conditions.

Evening primrose oil (EPO) which contains omega-6 fatty acids may also be of some help, as may Gingko biloba (see below). Invasive treatments such as a sympathectomy (usually a toxic chemical such as phenol is injected into a sympathetic ganglion to destroy the nerve), are not advised.

E. Headaches: another very common problem: the most frequent type are thumping/pulsing headaches: these are probably vascular in type, perhaps migraine. Indeed, symptoms such as neck stiffness, light intolerance and nausea/vomiting were common and quite a few people had one-sided headaches.

Blurred vision is also quite common on the affected side.

Most people seem to find lying down in a darkened room can help. Other than that, it's a question of finding some measure that helps you personally.

Although generally I would suggest cutting out caffeine, (it can worsen some neurogenic pain) it can be very useful when a headache first starts: 1-2 strong cups as soon as the headache comes on may help.

(If the patient is going to come off caffeine, be sure to do it very gradually as withdrawal can itself cause headaches).

Cold/warm compresses might also help. Wrapping up the face if going out in the cold or wind

may help to prevent triggering neuralgia/migraines. Feverfew (see below) is a useful herbal preparation for migrainous headaches, but it is important for patients to check that it's OK to take with their regular medications.

Opiates will not tend to be very helpful, in fact they might even be the cause on occasions (they tend to cause a low-grade headache that occurs almost all the time: this is known as a rebound headache).

Stopping consumption of foods that trigger headaches can also be very helpful, if they can be identified (this can be achieved by elimination or rotation diets).

Low blood sugar can be avoided by regular meals and eating low-sugar carbohydrates (e.g. bread, pasta) as these take longer to process and will give a more even blood sugar rather than a sudden rise which high sugar intake will cause.

Other techniques such as acupuncture, massage and cranialsacral therapy may be of use.

Fish-oil capsules have been studied in Cincinnati and it has been found that daily consumption may reduce the frequency of migraine attacks (60% of the study subjects reduced frequency from 2 a week to 2 a fortnight) as well as their severity.

F. Peripheral oedema/lymphoedema: this occurs in a small number of arachnoiditis patients: indeed, some may be diagnosed with CRPS Type 1 (previously known as Reflex Sympathetic Dystrophy) which is when there is neurogenic pain, swelling, discolouration of the skin in a limb after an injury: later stages may include osteopenia (loss of bone density) and skin/nail changes.

Other patients may develop peripheral oedema as a side-effect of medication: especially of steroids, opiates (morphine etc.) and NSAIDs. Measures such as raising the affected limb (usually legs) may help to reduce the problem.

Lymphoedema is a difficult condition to treat and requires specialist assessment. Manual lymphatic drainage used to be a beauty treatment but is now taught at the College of Naturopathic and Complementary Medicine.

G. Osteoporosis: reduced mobility increases the risk of this condition developing, especially in post-menopausal women: it may be necessary to consider prophylactic measures such as calcium supplements or a high calcium diet.

H. Thyroid disease: a recent survey found nearly 30 cases of thyroid disease amongst just over 300 arachnoiditis patients: the majority of these patients had undergone a myelogram previously (the remainder had also had invasive chemical insult to the spine).

It is helpful to bear this in mind when treating arachnoiditis patients who have a history of a myelogram as they may develop thyroid problems (the myelographic dyes containing the highest percentage of iodine presumably carry the highest risk).

I. Loss of sexual function: a very distressing problem that may have a devastating effect not only on the patient but also the relationship with his/her spouse/partner. This needs expert specialist management.

J. Fatigue: as in MS and fibromyalgia, (similar conditions) this can be a very debilitating problem. Learning to pace oneself and avoid overdoing things (and thereby being out of action for several days afterwards) is a vital measure.

There may be alternative treatments such as the use of rosemary essential oil (a few drops in a bath can be very reviving) which can be used on occasion should unusual events alter the normal routine.

Avoidance of abnormal sleep patterns is difficult, but a necessary step to counteracting daytime tiredness. It may be necessary to incorporate a short afternoon nap to help maintain enough energy to allow activities in the evening.

Fatigue may interfere to a large extent with social life, which can lead to increasing isolation. It is important to remember that sometimes fatigue is a symptom of depression (see below).

K. Depression: many arachnoiditis patients are extremely reluctant to admit to psychological distress, which is in large part due to being previously treated dismissively with the attitude that their problems are psychogenic or "all in the head";

Both doctors and patients must be aware that depression is an entirely understandable reaction to an incurable condition, which causes severe pain as well as loss of function.

There are a number of psychological stressors, including relationship and financial problems. Some of the problems will remain insoluble. Whilst it is best to commence with a strategy of psychological support (such as counselling), it must be recognised that depression may become persistent and significantly increase the suffering experienced by the patient.

Under these circumstances, medication may be helpful. Antidepressants are used in low doses for pain relief, but these are subtherapeutic with respect to antidepressant function. It may be appropriate for an increase of the medication already being used, or to add in a different drug (e.g. use of one of the newer drugs : SSRIs such as Prozac in addition to a tricyclic such as amitriptyline)