I know of so many people who struggle desperately towards the Holy Grail: the diagnosis of arachnoiditis.

However, it must be remembered that a diagnosis is only a starting point and often will not, of itself, contribute significantly to the management of the problems you face.

It can, of course, seem to confer a certain respectability and credibility.

It is important for the patient and the doctor to acknowledge to each other that the problems are complex and that they need to work together towards a better understanding of the nature of those problems and thence methods of controlling or removing them (this being regardless of or in the absence of a definitive diagnosis).

First off, we need to establish as closely as possible what the causes of the symptoms are (or indeed to exclude other conditions that may mimic arachnoiditis, notably Multiple Sclerosis, Systemic Lupus Erythematosus and fibromyalgia.)

TESTS:

Often you may find yourself undergoing a battery of different tests, some of which may be invasive (blood tests, lumbar puncture) and you may need chemicals injected into you for techniques such as MRI scans or X-rays (dye).

You will be asked about allergies before being injected with dye.

Invasive techniques around the spine carry small risks of serious adverse effects ranging from paralysis (rare) to post-lumbar puncture headache (severe but not lasting more than a couple of days usually) Longer-term adverse effects of spinal invasive procedures include, of course, arachnoiditis!

You must ask your doctor for a full and frank discussion of the possible risks.

For any test, you should ask yourself (and the doctor should be asking himself): will the results of this test make a difference to how my illness is treated? If the answer is "No" then the potential benefit of the test is non-existent.

TEST RESULTS NEGATIVE...SO NO PROBLEM??

Sometimes patients will emerge from all their tests apparently without anything clinically wrong with them: the test results all being negative.

The doctor (and the patient) must remember that no test is infallible and some are quite imprecise and may fail to pick up subtle signs. "False negatives" vary in their rate of occurrence depending on the test involved.

In any case, doctors should treat PATIENTS NOT TEST RESULTS!

It is imperative that the medical technology at the doctor's disposal does not exceed the humanity with which he/she applies the results to appropriate management of the patient's clinical problems.

WHAT'S WHAT WITH YOUR SYMPTOMS?

It is really important to remember the following points:

1. Not ALL of your symptoms will be due to arachnoiditis. If you get new symptoms or a sustained increase in old ones, (say 48 hours or more) then you should get medical advice.
2. EVERYONE gets aches and pains; it is unrealistic to expect to avoid these any more than "healthy people" can. Simple painkillers such as paracetamol/aspirin are often remarkably effective for problems such as tension headache, muscle aches (after exertion) or period pains. Just check with the pharmacist, though, before taking them, in case they interact with your prescribed medicines.

DIAGNOSIS OR NO DIAGNOSIS: A CHALLENGE TO TRUST?

Carl Jung wrote:

"Clinical diagnoses are important since they give the doctor a certain orientation; but they do not help the patient. The crucial thing is the story, for it alone shows the human background and the human suffering and only at that point can the doctor's therapy begin to operate."

Sometimes, it is not possible to reach a definitive diagnosis: this can be frustrating for the doctor and for the patient, and can lead to a loss of trust. It can also cause patients to feel terrible fear when they have unexplained symptoms.

However dreadful a diagnosis might be, in many ways, patients would often prefer the worst news to uncertainty.

If the doctor takes time to explain why a diagnosis is not possible and to reassure the patient that his/her symptoms will still be treatable and are not indicative of some undiscovered disease (such as cancer) then this should help to preserve the doctor-patient relationship.

It is vital for the doctor to stress that the patient can come back at any time to discuss new

symptoms that are worrying him/her.

For the patient's part, he/she must learn to accept that there is no diagnosis, just as he/she would have had to learn to come to terms with a known diagnosis: perhaps a way of counteracting the uncertainty is to remember that the illness you fear is not inevitable so long as it is not diagnosed: as Bernie Siegel has said: there is no such thing as false hope, but there is such a thing as "false no hope."

Doctors must, of course, keep in mind that the lack of evidence of a problem should not be taken as evidence of lack of that problem existing!

BENEFIT: RISK RATIO:

You may hear this term bandied about by doctors or see it in articles:
It basically means assessing the possible benefit of a procedure and potential risks it carries and balancing the two out.

HAVING TREATMENT: YES OR NO?

Firstly, patients must accept that *whatever* treatment they undergo, from a lowly aspirin to complex spinal operation, there are risks attached.

The second important factor to keep in mind is that once you are besieged by a chronic, incurable illness, you inevitably have far fewer options open: and this means that NOT having a treatment can itself carry negative consequences, and this must be taken into account when deciding whether to go ahead with the treatment or not.

Thirdly, there may be various different treatment options for each problem: you will need to decide which one is best for you. This decision may change over time: for instance, you may initially be best taking oral medication but need to undergo an operation at a later stage.

Chronic illness is a dynamic process, even if it is not "progressive" in the usual clinical sense of the word.

Doctors need to be prepared to explain the relative merits and demerits of the different available treatments (or of abstaining from these treatments) as fully as possible in order to allow the patient the opportunity for INFORMED choice and consent.

In the case of oral medication, a written consent form is not required, but there is a verbal consent, as it were, when the patient agrees to take the medication.