THE DOCTOR-PATIENT RELATIONSHIP. Or *THERAPEUTIC ALLIANCE*

THE PRESENT SITUATION:

All too often arachnoiditis patients find that they do not appear to be taken seriously by their doctors.

In fact, things may be so bad, that they are labelled with

"Abnormal Illness Behaviour."

This rather unpleasant term implies that you are behaving in a manner considered "over the top" by your doctors.

There are 2 points to remember about this:

1) The arachnoiditis syndrome causes complex and widespread symptoms, many of which may be due to unrelieved severe pain.

However, this picture is not widely known amongst doctors.It is therefore difficult for them to gauge what might be considered a "normal illness behaviour" for an arachnoiditis patient.

The typical clinical markers as suggested by Waddell are largely irrelevant: for instance, if the pain has become centralised, it is perfectly feasible for a patient to legitimately state that he/she has widespread pain outside of the usual "dermatome" distribution.

Central pain can also provoke a variety of bizarre, often indescribable sensations, all of which are highly unpleasant and distressing to the patient. In addition, unrelieved intractable pain itself can lead to a number of symptoms: anything from anxiety to heart disease.

Very little work has been done on the effects of chronic unrelieved pain, but recently Dr. Forest Tennant (widely known for his work on Addiction) has written about intractable pain as a

"disease, not a symptom."

2) It is known that of the number of people who present with chronic pain, the vast majority have an organic (i.e. physical) not a psychological problem.

This was demonstrated by a large study in the USA in the mid-90s.

Indeed, mental illness or malingering is highly unlikely to be the cause of the pain.

Dr.Muhammad Yunus (USA) in 1989 writing on the

"disturbed physician syndrome" (DPS):

referred to the experiences of fibromyalgia (FMS) Patients:

"DPS people are troubled because of their preoccupations that FMS patients are psychologically disturbed.

It is not the FMS patients who are disturbed, it is the physicians who are psychologically disturbed because they ignore the data and whatever data there is they manipulate to say what they want."

This is certainly just as true for arachnoiditis patients.

Once you have a diagnosis of a psychological problem, often this overshadows your condition to such an extent that any subsequent problems are deemed as being due to psychological causes rather than physical.

If you are fighting a court case, this can go back years, with the ?other side' dragging up psychological problems from the mists of time to question your credibility and thus the validity of your claim.

This is really dirty tactics.

A further point to bear in mind is that if you are involved in litigation, then it is more likely that you will be perceived as malingering or exaggerating your claim.

Strangely enough, it does seem that those few arachnoiditis patients, who are successful in their suit, don't get better once it has been settled!

Unfortunately, though, we must remember that, amongst the general population who claim invalidity benefits or who sue for compensation after an injury, there are a significant minority who are not genuine and these few tend to make life difficult for those of us who are genuine.

YES, WE DO HAVE PSYCHOLOGICAL PROBLEMS...BUT.

Of course we get some psychological reaction to our illness: if we DIDN'T we'd be abnormal!! (Or robots)

Let's not forget also that none of us live in a vacuum, and just as ?healthy' folk get problems (stresses and strains) through the pressures of daily life, so we do too, but with additional strains to cope with.

Just as ?normal' folk can get anxiety, or stress reaction, or depression due to circumstances, so we can too, and I suspect if you put anyone (including, and perhaps, especially, our doctors) to the test, a psychologist or psychiatrist would find something to fasten a label onto!

Pain inevitably wears the strongest of us down. As S. Weir Mitchell wrote (in 1872):

"Perhaps few persons who are not physicians can realize the influence which long-continued and unendurable pain may have upon the body and mind.... Under such torments the temper changes, the most amiable grow irritable, the soldier becomes a coward."

WHAT WE ARE LOOKING FOR.

The famous American surgeon, Bernie Siegel, who has worked closely with terminally ill patients and has written several books about his experiences, wrote the following on the subject of the doctor/patient relationship:

"An oncologist once told me:

?I view my relationship with my patient as a marriage.'

Now, that's the kind of doctor you want. You shouldn't feel intimidated by your doctor and you don't have to settle for one who is unresponsive. Make sure that your doctor is treating you as a person and not just a medical condition; don't be what I call a "submissive sufferer".

And trust your intuition. Think about what kind of course of treatment you can live with and make your own decisions accordingly. It's your life, not your doctor's."

Doctors should remember Albert Schweitzer's words:

"We must all die. But if I can save (a person) from days of torture, that is what I feel is a great and ever new privilege. Pain is a more terrible lord of mankind than even death itself."

Of course, many pain specialists are highly sensitive to the needs of chronic pain patients: they can sympathise, but few of them have experienced chronic pain, so it is hard for them to truly empathise (put themselves in our shoes)

What we, as patients, must remember, is that whilst our illness is our prime concern 24 hours a day, 7 days a week, our illness is our doctor's concern for maybe 10 minutes every month (or however often you visit).

It simply isn't feasible for him/her to spend more time on us as individuals when he/she has a waiting room full of other patients to see to.

However, what the doctor must aim for is to be able, in the short time allotted to each patient, to give his/her FULL attention to bear on the patient's problems; to be compassionate and to really LISTEN.

As the essayist Anatole Broyard wrote in "Intoxicated by my Illness.":

" Not every patient can be saved, but his illness may be eased by the way the doctor responds to him.....(the doctor) must see that his silence and neutrality are unnatural. It may be necessary to give up some of his authority in exchange for his humanity, but as the old family doctors knew, this is not a bad bargain."

He also wrote:

"I wouldn't demand a lot of my doctor's time. I just wish he would brood on my situation for perhaps five minutes, that he would give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh to get at my illness, for each man is ill in his own way. Without such recognition I am nothing but my illness."

THERAPEUTIC ALLIANCE

J.S. Hochman, M.D., Executive Director of The National Foundation for the Treatment of Pain (in the USA) wrote an article called "Perspectives In Intractable Pain Management in 1998.

He suggested that

"a strong **therapeutic alliance** is a significant predictor of success".

In my dictionary, the term ?Alliance' is defined as "a union formed by agreement; joining of interests"; synonyms: coalition united front.

?Therapeutic': of, or having to do with, the treating or curing of disease; a therapeutist comes from the Greek therapeutikos or therapeutes: one ministering. Synonyms for therapeutic in the Thesaurus include medical care, treatment.

Alliance has connotations of standing united against all comers: in this case, against the enemy: the illness.

Therapeutic doesn't necessarily mean curative, but also has to do with treatment.

In order, then, to make progress, we need to forge an alliance between the doctor(s) and the patient. The best way to do this is to have a one-to-one relationship.

Although I repeatedly stress that the complex nature of the arachnoiditis syndrome requires a multidisciplinary approach, (by definition involving various medical and paramedical teams) I must also stress the importance of a single person overseeing the whole process.

This is probably going to be your GP: whose role is "primary care": he/ she is on the ?frontline' so to speak.

Make no mistake, **fighting** chronic pain is very much an appropriate analogy in many ways but later on I will be urging you to **accept** the situation, which seems the converse: in reality, it is a delicate balance between the 2 approaches.

I suppose it is in essence a question of accepting the inevitability of the warfare: and turning our hand to marshalling our resources and allies and not wasting our ammunition on each other.

Dr. Hochman stated:

"Long-term treatment is also always more reliable than brief intervention, and in-depth knowledge of the patients, their diagnoses, and their course in treatment is an essential and powerful positive influence - for the reduction of pain, for effectiveness of pain medication and rehabilitative interventions, for the reduction of the need for medication, and for the avoidance of tolerance, diversion or recreational abuse of medications.

When patients unequivocally know that they are well-known to the treating physician, abuse of treatment is highly unlikely."

By the same token, the patient knows that he/she doesn't have to go over old ground every time there is a visit; his/her temperament, family situation and ongoing stresses and strains are well known to the doctor and therefore emotional reactions or need for increased medication are more likely to be taken in their proper context.

So let's make the first step the establishment of trust and a mutual respect between the patient and the doctor: the doctor must be prepared to accept what the patient is telling him/her as genuine and that any psychological distress is likely to be a CONSEQUENCE of chronic illness rather than the cause of it.

On the patient's side, he/she must be prepared to take some responsibility for any progress made in treatment: it is imperative that he/she realises that there is no magic wand, that the doctor cannot have all the answers.