

"Trust determines the space for future interactions between parties.

Distrust closes down possibilities - trust opens them up" Peter Keen

Peter Keen was discussing economics, but as we are often dealing with the medical aftermath of a triumph of economics over ethics, I think the quote is highly apposite.

Those of us with arachnoiditis are accustomed to having our trust in human nature betrayed, and our trust in the medical profession dissolves pretty quickly in a climate of unrelieved pain and lack of help from those whose help we need most.

However, we must be vigilant that we don't extrapolate that lack of trust to other people around us.

All too often, people 'fall out' with each other because of some perceived slight or a minor misunderstanding.

At its worst, this undermines not only the individuals but also the groups to which they belong.

One of the primary problems is that the perceived aims of support groups and the methods they employ to achieve them are difficult to define in a condition as complex and contentious as arachnoiditis.

Group members have expectations that may be failed in some way or another, often because groups are run by folk who are themselves struggling with the illness.

In reality, we have all been let down, and let down badly, by the medical profession which has failed to conduct the necessary research and still fails to acknowledge the extent of the problem.

We are let down by government agencies that fail to regulate pharmaceutical products appropriately, and by drug companies who manufacture the poisons that have wreaked havoc in our nervous systems.

There are no easy answers, no quick way of finding suitable redress for lifetimes of suffering. Yet we all want results NOW, and an end to our pain, and in a wider context, ways of making sure other people aren't subjected to the same damage.

We forget our targets at our peril...or perhaps they simply become hazy?

Who or what are we fighting?

Firstly, we are fighting the illness and the pain and suffering it causes. We must guard against displacing our anger about the injustice of life in inflicting this upon us onto other targets.

Secondly, the institutions that made it possible for the condition to be caused. By that I refer to the government agencies (licensing authorities etc.) and the medical profession.

We should not be fighting each other!

How we can effectively fight is not an easy matter to define.

This is where the problems seem to lie. There is immense frustration at our powerlessness, especially that which we face, alone, day by day, with our individual struggles, translated into a wider arena, making our voices heard. This can spill over into distrust of other peoples' motives when there is no apparent progress.

I feel that it is all about the issue of trust.

The point about trust is that it is a mutual phenomenon.

We need to trust each other.

That means we need to define what we expect of each other and broadly speaking that boils down to defined behaviour under defined circumstances. Reality arachnoiditis-style is much less simple and can't be narrowed into neat little conceptual packages.

This means that perhaps we have to settle for the next best thing: trust that we have each other's best interests at heart.

That doesn't mean we'd take a bullet for each other, but simply that we'll do our utmost to ensure that we don't act in a way that is detrimental to the other's wellbeing.

There is only one point we must all keep in mind: United we stand, divided we fall.

Like the advert with the polar bear and the ant: a lone voice can't shift a massive obstacle, whereas thousands of united voices can move what seems immovable.

“The man who trusts men will make fewer mistakes than he who distrusts them”

--Camillo di Cavour