

"We minimise another's loss

when reminding him or her

that others suffer too."

Dr. Ann Kaiser Stearns.

People in pain may talk in a kind of 'code' in which nothing is at all clear and there is frustration on both sides.

The following communication tips may help:

1. **Listen:** this may involve ensuring no distractions and ensuring focussed attention, and even 'reading between the lines': Bernard Lowen notes that "the majority of people's complaints are relatively straightforward, detectable to the ear cultivated to listen to the inaudible sigh, visible to the eye sensitive to the unshed tear."

2. **Be genuine:** it isn't much fun listening to someone talk about being in pain, so don't undertake to listen unless you're really prepared to do so willingly. Only listen for as long as you want to; 5 minutes of proper listening is better than 20 minutes of reluctance and you don't have to have all the answers.

3. **Be aware:** that the sufferer may be reluctant/afraid to say how they are feeling: they may wonder what the point is, or worry that you won't believe them; they may understate their pain. "I feel fine" may be their way of avoiding the issue and have no real bearing on the pain they are experiencing.

4. **Look for non-verbal clues:** such as pale, drawn face, sweating, lack of facial expression, generalised body tension, holding the body still, restlessness, sleep disturbance, difficulty concentrating, irritability, decreased activity, depression; Chronic pain sufferers tend not to show obvious signs such as wincing, grimacing, moaning (except with acute

exacerbations such as muscle spasms) which 'healthy' folk might show if they injure themselves, for example. Depression may lead to reduced expression of pain.

5. **Believe the person:** not being believed adds to the level of suffering considerably. It is a myth that chronic pain sufferers exaggerate their pain to gain sympathy or avoid responsibilities

6. **Ask 'helpful' questions:** which can stimulate hope: specific or open-ended queries may convey your understanding and desire to help. Asking the person to rate their pain on a scale of 0-10 (see below) may help. Being asked the right questions allows the pain sufferer to talk about their pain.

7. **Avoid thoughtless comments:** throwaway lines such as 'you don't look sick' or 'you'll just have to learn to live with it' are unhelpful and may be damaging; fear and anxiety don't motivate constructive behaviour. For someone at the end of their tether, a comment such as, 'You have done incredibly well to cope' may help to evoke a sense of strength and determination to carry on.

8. **Be compassionate:** As Bourne wrote: 'There are sympathetic doctors, relatives, and friends who expect the patient to be brave, stoical, and cheerful. In the end the patient yearns for less exhortation and more compassion. Compassion is an important consequence of comprehension of the existence and nature of arachnoiditis.'

9. **Be honest about the limitations of your own knowledge:** don't pretend you have all the answers! Sometimes well-meaning advice can be inappropriate if it isn't based on understanding of the condition.

10. **Bear in mind:** that chronic pain is not the same as any pain you, as a healthy person, have experienced. Neuropathic pain such as that in arachnoiditis is a particular type of pain not experienced by people with an undamaged nervous system. It causes severe, unremitting pain and this is often resistant to treatment. It may also cause bizarre symptoms which seem unlikely, such as pain in numb areas.

Do's and Don't for Families and Friends of People with Arachnoiditis:

This list has been adapted and expanded from one posted to the American online support group, [COFWA](#) :

**DON'T** assume that just because I look OK I feel OK. I'm very good at looking completely normal but feeling terrible.

**DON'T** tell me you know how I feel\*

**DON'T** tell me about your aunt Hilda and her arachnoiditis, and how well she manages in spite of it, that just makes me feel inadequate; I'm doing my best.

**DON'T** tell me "It could be worse", I know that already and don't want to be reminded!

**DON'T** decide what I'm capable of doing or not doing; I want to make my own decisions (even the wrong ones!)

**DON'T** be upset that you can't ease my pain: or at least, try not to get upset

**DON'T** ask me how I feel unless you really want to know and are prepared to actually listen to me.

**DON'T** assume because I did something yesterday that I can do it today, as arachnoiditis can vary from day to day.

**DON'T** expect me to get enthusiastic about the latest fad 'cure', or assume that my not being willing to try it means I'm not fully committed to 'getting better'.

**DON'T** look at me as if I've lost my marbles when I forget things: you'd be comatose on the medication I'm on!

**DON'T** criticise my organisational/culinary/housekeeping/ etc. skills: I'm doing my best. I do know I'm not doing a great job, but at least I'm trying!

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**DO** learn as much as you can about my illness so that you have a better understanding.

**DO** realise that when I get irritable and frustrated, it is likely to be with the disease and not with you

**DO** tell me about your troubles; it's nice to feel I can help YOU for a change and I still have a good pair of listening ears.

**DO** let me know how YOU feel about my illness and how it affects you; I know it's not easy for you, and it's harder for me not to know how you feel than to hear you have a bit of a moan.

**DO** realise that my illness doesn't make your problems invalid.

**DO** let me know if you want to help and when and how you are available to do that.

**DO** understand why I may cancel plans at the eleventh hour; I'm not antisocial, it's just that arachnoiditis can be unpredictable.

**DO** give me loads of encouragement: gentle hugs are great, but not too hearty, I hurt in places you can't imagine.

**DO** understand that I might not be much company when the pain is bad, whether in person, or on the phone.

**DO** realise that by the evening, I feel as if I've had the stuffing knocked out of me and my concentration levels are on a par with a goldfish: you could just as well be speaking to me in a foreign language!

**DO** carry on inviting me to go out, sometimes I might actually be able to accept the invitation!

\*"Empathy disconcerts as often as it comforts"

(Kramer P. Empathic Immersion. In: Spiro HM, Curnen MGM, Preshel E, St. James D, Eds. Empathy and the Practice of Medicine: Beyond Pills and the Scalpel. New Haven: Yale University Press, 1993:174-189.)