

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!
- 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" ([\[1\]](#))

[\[1\]](#) 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