

long term prognosis

Posted by Ang - 09 Dec 2005 21:45

Hello my name is Ang and I have joined this forum on behalf of my 34 year old sister who has been dx'd with AA in Sept. In my endless search for answers, I have come to realize that there simply aren't any. I have become increasingly depressed when I read posts on how victims are so disabled. She has had 2 surgeries including spinal fusion and 8-9 ESI. All along we thought well maybe it will be bad for a time into it gets stablized. Well thinks just keep getting worse

What I would like to know is if the kind Dr. Sarah could address the long term prognosis in most patients? Most being the key word, because I do know the disease is so unpredictable. But with the right pain control (which my sister does not at this time, she will be seeing a new pain spec. soon) CAN the disease be kept at bay? I know that this is a loaded question but any response would be greatly appreciated.

Thank you Kim, Ann and Dr. Sarah for the attention to my question. It is my first time so please forgive me for a lengthy question.

Best to all,

Ang

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Re:long term prognosis

Posted by DocSarah - 10 Dec 2005 19:29

Dear Ang,

I feel for you as you are clearly so worried about your sister. It is easy to get the impression that everyone with arachnoiditis has a grim life and is very disabled. This is partly because many of the online groups have a lot of members who are on the severe end of the spectrum.

The bottom line is that none of us have a crystal ball, and that arachnoiditis is incurable. BUT (and this is a big but) many people manage a good quality of life despite the condition and only a minority become severely disabled.

Generally, the pattern is that after an initial period of deterioration (usually linked to some event such as surgery/trauma) there is a 'plateau phase' in which there is stability, albeit with ups and downs ('flare-ups

and remissions') much as with many chronic inflammatory conditions.

The people who stay as active as possible and take sensible medication on a regular basis (enough to give some pain relief but usually not complete eradication, at the lowest effective dose) tend to do best. This requires a broad-based plan tackling all the different problems, so one mode of treatment (e.g. tablets) is generally not enough to make a big difference: it takes a combination of medication, gentle exercise, massage, etc. (see other parts of this website for details) and most importantly a realistic approach but an optimistic one.

I hope you and your sister find the website helpful. Try not to get too down. I've had arach. for many years and I still manage a good life despite it! 🍷

All the best,

DocSarah

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Re:long term prognosis

Posted by Ang - 11 Dec 2005 14:50

Thank you so much DocSarah, worst can not express the hope you gave me in your reply. I just wish that she could enter the stablization phase. She had spinal fusion in Jan 05 followed by 2 more ESI's in Aug and Sept until finally diagnosed. She really is homebound although not bedbound. Could this mean that things could improve once the body adjusts to the damage done by the last ESI. I truly hope so.

Another question which I have not really read much about is; Does AA affect the female menstrual cycle. My sister has always had problems in that area however lately she gets cyst after cyst and her cycle can not be controlled. Her endocrologist says the AA could contribute to much more painful cycles. Are you aware of any connection?

Again, thank you for providing with some hope. You so kind to offer your experiences and expertise to people who need it so desperately.

My sincerest appreciation,

Ang

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Re:long term prognosis

Posted by DocSarah - 11 Dec 2005 17:34

Dear Ang,

glad you are a little reassured.

The hormonal problems can be a feature of AA, or indeed any chronic pain problem, because of the effect on the hypothalamus which is connected with the pituitary gland that the is main centre for hormones (via something called the hypothalamic-pituitary axis). Has she found taking the oral contraceptive pill any help?

Regards,

DocSarah

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Re:long term prognosis

Posted by Ang - 11 Dec 2005 19:25

DocSarah,

Yes she has tried many pills and well as as Lupron as Depopravera(sorry spelling) nothing seems to stop her cycle and there is increased pain at ovulation(usually resulting is cyst ruptures) as well as menstration. DocSarah is it possible that with documented AA in lumbar area, it affects the hypothalmus? Does the AA spread? and that quickly?

Having you to look to has been godsend.

Thank you

Ang

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Re:long term prognosis

Posted by Ang - 12 Dec 2005 04:43

DocSarah,

I am so sorry for throwing so many questions at you but I am searching so desperately for answers. In regards to my previous question, I have read some more of your incredibly informative articles on the autonomic nervous system. My sister seems to be affected by every symptom you mentioned, does this mean she has the advanced stage of the disease? Do the degree and quantity of symptoms present shed light on the long term prognosis of the disease? Once again my anxiety rises when I read in detail.

There seems to be no cure for autonomic dysfunction, does this dysfunction shorten one's life. Looking back she has had AA in my opinion for so long which has now progressed with the additional surgery and ESI's.

Thank you so much for all your time and attention.

May God bless you and your family?

Sincerest thanks,

Ang

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