

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 Ang - 13 Dec 2005 01:24

Oh DocSarah,

I guess it, I so often dispair. I am so afraid that the AA is in her entire spine, often complicating every part of her body. For a year now, life day to day is so challenging. I pray that she can have quality of life. Her quality of life is so important to me not to mention her 2 little girls (4 and 2)

One thing I had asked is, Can documented AA in lumbar area affect the hypothalamus and upper limbs (arm and hand, including stiffness and spasms not to mention pain, one side of the body) The centralized pain you mention is a bit confusing.

Thank sooo much.

Respectfully,

Ang

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Re:long term prognosis

Posted by Ang - 13 Dec 2005 03:54

DocSarah,

I'm sorry I forgot to mention this in previous post.

DocSarah, for AA patients is this a common thing, sometimes I wonder that even though the doctors see the AA in lumbar area, I feel they are missing something in the cervical MRI

this often happens to my sister is this common:

She calls it a nerve crisis:

Severe pain in the back travels up and down spine then her entire left side, including leg up to her big toe and in the arm includes all fingers, everything gets stiff(unable to move at all) and pins and needles. She takes Actiq lollipop and about hour, hour and half later she regains some movement that slowly returns several hours later. Is this AA related in your expert opinion?

I am so lucky to have found you.

Best to you and your family,

Ang

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Re:long term prognosis

Posted by DocSarah - 16 Dec 2005 11:44

Hi Ang,

it may well be what you describe your sister experiencing as 'nerve crisis' is just that, the body being on constant 'red alert' when there is unrelieved chronic pain, sometimes a mild harmless stimulus (can be something as simple as needing to go to the toilet) can precipitate a big reaction. It doesn't mean that AA has spread all over the body though.

Hope this helps,

DocSarah

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Re:long term prognosis

Posted by Ang - 20 Dec 2005 21:35

Hi DocSarah

I wish you and your family very healthy and happy holiday. I know this time of year is very hectic for most and appreciate your time.

So is it safe to assume that the involvement of your upper limbs (as new symptoms and that her neck MRI showing herniation on C5,6) does not necessarily mean the AA is advancing. It is just that the symptoms are the same as in the legs. She loses the ability to move her arm at all. Is this a possible benign situation? Does this occur in most patients? I hope that the questions are not too repetitive but I'm still confused. Most likely she got the AA from ESI's and from a lot of literature that is a known culprit of progressing the AA to other parts of the body.

Please DocSarah, I'm just trying to find out if her symptoms are consistent with the AA diagnosis especially with the involvement of the arm (whole left side) and severe headaches.

As an aside, a pain doctor today suggested botusim shots to the muscles that get severe spasms. Is this advisable?

As always, ever grateful.

Best to you

Ang

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Re:long term prognosis

Posted by DocSarah - 20 Dec 2005 21:48

Hi Ang,

the chances are that the upper body symptoms don't mean AA has spread, but it does all need checking out to exclude this or other problems in the neck area.

The headaches again are common in AA but should be checked out to exclude other causes.

Although AA causes a wide variety of symptoms, it is always vital to ensure no other cause is responsible for new or persistent symptoms.

I wish you and your family a lovely Xmas.

Regards,

DocSarah

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Re:long term prognosis

Posted by Ang - 30 Jan 2006 22:30

Hi DocSarah

My sister has had increased pain levels with the need to increase her meds, she is only 34 and has had this disease for a short time. Her body just does not want or cannot stabilize or "plateau". You mentioned previously that you have had AA and manage a life inspite of it. How do you do it?

I have been so afraid especially after reading that eventually the nerve endings will calcify and that the progression just does not stop.Is it true that with the "end result" of the disease one will not be able to walk. I guess what I am really asking is for some encouragement that things will get better.

Thanks in advance for your response, I look forward to receiving it.

Ang

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