

difficult to find doctors

Posted by ann - 30 Nov 2005 21:06

hello doc sarah.

can you answer this e-mail that has come in please... ann

I have learned so much from this site. Could someone please let me know if there is any promising treatments for this horrible disease and what the most common prognosis is for victims? My 34 year old sister has been dx's and it has been difficult to find doctors who are aware of the condition. Will this disease shorten her life or put her in a wheelchair. Thank you so much for any input.

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Re:difficult to find doctors

Posted by DocSarah - 01 Dec 2005 20:49

Hi Ann,

please pass on the following:

Hi I'm sorry to hear about your sister.

Sadly, there is little research into the condition, and few doctors who specialise in it. You don't say where you are (UK/US/Australia/New Zealand??)

IN the States, you could try Charles Burton in Minnesota or Professor Aldrete in Florida.

In the UK I can see patients if they can travel to Devon where I am based, and of course I am happy to answer general queries via the forum.

Most people 'plateau out' i.e. stabilise and few end up immobile enough to need a wheelchair. Treatment involves combating the symptoms and needs to tackle various different aspects of the condition such as the musculoskeletal pain and the neuropathic (nerve) pain for instance. It is vital to take adequate pain relief, although this is with the aim of managing the pain rather than eliminating it altogether. It is also important to maintain as good a mobility as possible to prevent deconditioning. Hopefully you can find out lots more useful info. on this website in the various articles.

All the best,

Regards,

DocSarah

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Re:difficult to find doctors

Posted by Kim - 02 Dec 2005 16:09

Thanks Ann for keeping things upto speed for me. I am not 100% yet but have had some answers as to why things are going wrong!

I was particularly interested in this email because it contains that 'old chestnut' Arach "will shorten your life by 12 years". This came about by a particular review of research documents by a chap called Guyer. The Doc has him referenced somewhere and a quick search should find it. It was the most appalling rubbish I have read and was only highlighted because of the scare tactics it could produce. The bottom line here is that there has not been a good quality study of Arachnoiditis, it's causes or outcomes. As one consultant said famously about Myodil victims - "Why should we, they are a dying breed anyway"!

As for is it progressive? I asked the doc to do this article for me, as it was always one of the biggest worries on the helpline. As you know I am not medically qualified but - Having talked personally to thousands of people, diagnosed and undiagnosed - my opinion is that in the main it is not progressive but as we get older - we cope with it less well. That is not the same as saying we give into it - not true for many people. Our bodies are older and we also tend to compensate movements to help relieve the pain. Our Immune Systems are wearing this. I know that someone only has to sneeze in the same room and I am practically down with pneumonia!

As for a wheelchair - well that will be your sisters choice and what suits her. I am not in a wheelchair and that does put some limits in my life. I would love to visit the Eden Project here in England but know I couldn't manage the walk. Some people tell me that's selfish of me, well maybe it is but it is how I want to live my life now. That's all I have got. There may come a time when the benefits out weigh my reluctance to give up my mobility but I think I will recognise that time when or if it comes.

Here ended the layman lesson!

That's all I can manage for now

Be back soon

Kim