

### "Twinitis"

Our mother June who adopted us at 6 weeks has been witness to this progressive disease for a couple of decades now. Jayne, the slightly older, (by minutes although it felt like days on the way out) knows much more about AS than I do. That's probably because she experiences worse symptoms than I do and/or I'm partially in denial – a road accident that I had about a decade ago led to 5 years of severe epilepsy aka spontaneous combustion. I nominate Jayne as the professional patient on the subject of ankylosing spondylitis – and me as still learning.

**Q. (John):** What differences have you recognized between the two of us?

**A. (Jayne):** My first sign of trouble was a continuing pain in the sacrum (pelvic area) from the age of 18. I was finally diagnosed at about 22. It was 3 years later that a pain clinic diagnosed me with fibromyalgia. As far as I know there isn't a link between the 2 conditions. What I have noticed in John since he returned from the warm climes of the Far East to the much cooler and damper weather of the Thames Valley region, is the onset of pain and stiffness in the sacrum. He was 35 then. As someone with AS, I saw

similarities and differences in him that I could relate to.

I urged him several times to see a rheumatologist but unlike me, he blocked it for several years until he had no option because of the pain and stiffness. The result, as I suspected, was a clear diagnosis of AS by X-ray and blood tests (HLA B27 positive). I was surprised and concerned to see that the fusion of his SI joints was marginally worse than my own.

**Q. (John):** On that happy note dear twin, how do you think this affected us both psychologically?

**A. (Jayne):** Great concern for our future. Reflecting on the years of illness with fatigue (both mental and physical) I had experienced, I was worried how John was going to cope with accepting it. That meant managing with the limitations he was going to encounter. I knew that the fast paced life John had been leading was going to gradually and severely slow down. This whole situation with him was amplified by his serious head injury/epilepsy.

**Q. (Jayne):** Can we simplify our similarities and differences with AS using a type of chart? Shall we call it the "twinitis" scale?

**Pain Scale is 1–10**

(10 being the highest pain level)  
using worst day scenario

Location	Jayne	John
Rib Cage	9	8.5
Lumbar	8	8
Sacrum	6.5	9
Coccyx	5	5
Thoracic	4	4
Cervical (neck)	8	6
Chest (sternum)	8.5	7.5
Knees	3.5	6.5
Feet	3.5	1.5
Eyes (iritis)	x 3	0
Urethra (inflammation)	Yes	Yes
Hips	8	4

... (John): We would have to mention that both of us have other health problems which may affect these results. Our thanks to all the staff at Datchet Heath Centre and my personal thanks to Dr Martin Chan, GP. Comments and feedback welcome to Jayne at jayne.crampton@btinternet.com - or myself: john.crampton4@btinternet.com

**John Crampton**

*It is interesting to note the differences between the symptoms Jayne and John experience. Women may present slightly differently with more emphasis on peripheral disease (knees, hips, feet etc) while men have more emphasis on problems with the spine. And refreshing to see a GP getting a thank you!*

*Jane Skerrett*



John and Jayne Crampton