Cheating Death: Inflammation, Pain & Living
With Ankylosing Spondylitis

Alexander Hayes
alex@alexanderhayes.com
www.alexanderhayes.com

Keywords

ankylosing-spondylitis, spondyloarthropathies (SpA), HLA-B27, IL23R, ARTS1, AAU, ERAP-1, arthritis, pain, medication, rheumatology, prevention, plan, management, NSAID, symptoms, etanercept, immune, bDMARDs, uveitis, exercise, diet

Disclaimer

This short paper provides an account of my personal experiences only. I am NOT a medical practitioner nor am I authorised in any way to provide medical advice so please consult with your medical practitioner.

Abstract

Ankylosing Spondylitis¹ is a medical condition which causes inflammation and pain with a range of symptoms that affect a small percentage of the human population. This short paper provides a personal account of these symptoms and associated musculoskeletal intervention by rheumatologists² I have experienced over a thirty year period. The paper seeks to bring awareness as a case example for others to better understand how to recognise, seek medical assistance and manage this debilitating condition which can lead to severe disability. There are no known cures for this condition yet there are many preventative measures which may assist in alleviating often debilitating effects of this condition. Clinical trials (limited AU trials) of the biopharmaceutical Etanercept³ (also known as Enbrel) are looking promising for Ankylosing Spondylitis.

¹ http://www.arthritisaustralia.com.au/images/stories/Michael_Slater/Pg_2_What_is_AS.pdf
² http://www.rheumatology.org/I-Am-A/Patient-Caregiver/Health-Care-Team/What-is-a-Rheumatologist
³ https://en.wikipedia.org/wiki/Etanercept

Final - 1st July, 2016
Photo - 2016 - The author in hospital with acute pericarditis
Introduction

I am writing this short article with the intent of sharing my personal experience in the hope that it might save another person's life or at the very least bring others into the awareness of the medical condition called Ankylosing Spondylitis.

In itself ankylosing spondylitis is not a life threatening condition but in this short paper I will describe recent events that could well have led to my untimely departure. I am not seeking to highlight malpractice rather provide detail regarding the immediate and long term symptomatic aspects of the condition as well as how I have managed the condition over thirty years.

In hindsight, the path I took to cope with the condition has in many ways contributed to the mismanagement of the condition and so this paper also provides in conclusion a number of strategies that I've employed with reference to learned lessons over the years.

The Diagnosis

At age 14, after persistent complaints of a sore back and one visit to a rheumatologist, with a simple blood test I was informed that I had a fancy gene marker called HLA-B27. At the time a further two genes were mentioned that could be associated with Ankylosing Spondylitis namely IL23R and ARTS1.

Ankylosing Spondylitis as a condition is well documented and I had plenty of time (pre-internet) to scour libraries and other medical literature to better understand what I had been tagged with. I discovered that Ankylosing Spondylitis affects less than 2% of the entire human population and across that two percent that Ankylosing Spondylitis is three times more likely to occur in males than females with symptoms first appearing between the ages of 15 through till 45.

I so happened to be one of the lucky few early onset cases, which, given I’m 47 years old now means I’ve been having recurrent bouts of symptoms over thirty years.
What Is Ankylosing Spondylitis?

According to Ankylosing Spondylitis Australia:

Ankylosing spondylitis (AS) is a disease which causes inflammation and pain in your spine (backbone). It can also affect other joints such as the shoulders, hips, knees, ankles and the joints between your ribs and breastbone.

That article goes on to describe that although in almost all cases the gene is hereditary only one in every eight carriers will develop symptoms at all and a further case being that if one or more other sibling has Ankylosing Spondylitis they too are likely to have a manifestation of Ankylosing Spondylitis.

In addition to musculoskeletal issues people with Ankylosing Spondylitis may also experience:

“...Iritis which involves short periods of eye inflammation which results in red and sore eyes, blurry vision and can cause permanent damage if left untreated. Another known aspect of ankylosing spondylitis is the lining of the bowel may also be affected, causing symptoms of inflammatory bowel disease such as diarrhoea and bloating.”

If you do the math you will know that this all combined means I’m one of the few people to have all full blown aspects of the condition. So for as long as I can remember I’ve had medical staff ask me “…so how would you rate your current pain out of ten where 10 is the worst pain of all and you are screaming in agony.”

My replies were generally between 8 and nine out of ten because if I was presenting to a medical practitioner generally my symptoms were acute or at least at a threshold unduly affecting my quality of life. The fact being that for most of my waking hours I exist (during inflammation periods) in a state of pain between zero and that intolerable threshold.

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4 http://www.arthritisaustralia.com.au/images/stories/Michael_Slater/Pg_2_What_is_AS.pdf
5 http://www.arthritisaustralia.com.au/images/stories/Michael_Slater/Pg_2_What_is_AS.pdf
Symptoms of Ankylosing Spondylitis (for me)

I’ve decided to detail in rank order of what I think have been symptoms of Ankylosing Spondylitis; onset (and disappeared mysteriously), mild (persistent and unpleasant), severe (affecting my behaviour and mobility) or extreme (hospitalization);

- **Onset**—4/10 pain—joints that would seize up and cease functioning such as fingers and toes—at least once a year;
- **Mild**—5/10 pain—dull frontal lobe headaches, chest pain in breastplate, ribs, neck, hips and lower lumbar region of spine—persistent, everyday and worse during winter months or when under stressful life conditions;
- **Severe**—6 or 7 out of 10—neck pain (car accidents and fights), ribcage (breaks and falls), knee pain (breaks) and shoulder (breaks)—in each case ankylosing spondylitis over compensates for trauma and causes more inflammation, bursitis and edema buildup;
- **Extreme**—9 out of 10—hospitalisation on several occasions with extreme iritis in both eyes causing temporary blindness, migraine; pericarditis where heart attack like symptoms are treated without due consideration of the ankylosing spondylitis symptoms

So in lay terms I have been in constant pain for almost thirty years of my life. I have almost always had a persistent headache, joint pain and sensitive eyes.

It is important now to break down what I’ve been experiencing and explore what I believe all have links in some form or another. I have laid these out as experiential accounts in an escalation from low to high grade concern.
Escalation - An Experiential Account

I acknowledge that there may have been causal agencies that have caused one or more of these experiences to manifest themselves that could well have been avoided. In some cases they may be unrelated but please keep in mind that the following experiential account is an observation of my general state over many years.

A medical practitioner would tell you (as they did me on many occasions) that many of these experiences or symptomatic accounts are unrelated. I am curious however as to whether that is indeed the case given my observations over thirty years and how many other Ankylosing Spondylitis patients would concur with my experience.

1.0 Anxiety

I note during bouts of inflammation or “attacks” where the symptoms are acute and persistent that my general levels of anxiety are raised to a sometimes debilitating level. It’s well known that tiredness due to pain and discomfort coupled with trauma such as injury or emotional stress can bring on these anxiety conditions which in turn duly affect the way an inflammatory condition manifests itself, with sleeplessness or insomnia a very present factor. I often note a present heartbeat (where I am aware of my pulse) in my temples at these times of inflammation. On average, due bouts of increased inflammation I note my blood pressure rises to within the first level of hypertension.

2.0 Tiredness / Sleep

Over many years I’ve noted an increasing state of tiredness mainly due to the presence of low grade pain or in response to the medications I’ve been prescribed to counteract the effects of ankylosing spondylitis. I know for a fact now that general NSAIDs such as Meloxicam and Naproxen have had a far better result that others previously thought as “core” solutions such as sulfur based drugs. My tiredness translates into nodding off during inactive periods resting through to extremes such as while reading a book to a child. Accompanying tiredness is the omnipresent experience of insomnia, restless legs or rapid thought processing during times of inflammation interrupting my sleep which in turn affects my tiredness levels and moods.

3.0 Exercise

When my Ankylosing Spondylitis conditions are present I find it much harder to find the motivation to push through tiredness and pain to exercise but generally I find after the

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6 http://www.uptodate.com/contents/nonsteroidal-antiinflammatory-drugs-nsaids-beyond-the-basics
7 https://www.drugs.com/meloxicam.html
8 https://www.drugs.com/naprosyn.html
activity that I am feeling better and more alert. When I have no ankylosing spondylitis symptoms I am often able to exercise for long periods of time with good results. Exercise in general is one of the best antidotes to Ankylosing Spondylitis which I describe in my conclusion and I continue to pursue cardiovascular activity that combines full skeletal muscle activity such as running, cycling and swimming.

4.0 Diet

I find myself during bouts of Ankylosing Spondylitis inflammation craving high sugar foods, yeasty or fatty products and I attribute that often to the medications affect on my general system and mood. My diet often has a direct affect on my mood and in turn affects my pain threshold as the food types themselves affect the pain thresholds.

5.0 Irritation

My behaviour has at times when I’ve noted inflammation being present fluctuate between states of general happiness to periods of feeling low and lethargic, with a noted shift according to the level of medications to counteract Ankylosing Spondylitis including NSAIDs, pain blocking drugs like Panadeine Forte (containing Codeine) or other. In general, the higher the dosage of drugs that kill the pain but have little effect on the inflammation the less likely I have had success over the long term managing the condition. The presence of codeine also whilst alleviating the pain does little to manage the inflammation and causes me to become belligerent (according to others).

6.0 Tinnitus

I often note ringing ears or tinnitus as the pain associated with inflammation escalates and as medications increase. I often need to drink far more water during these periods and it is important to note that I often have “ringing switches” where the ringing will switch to one ear only for long periods of time, sometimes weeks at a time.

7.0 Headaches

I continue to experience frontal lobe headaches, temple located headaches, full cranium migraines and “gut” based headaches that include nausea, cramping and even vomiting. I’ve noted locked jaw, severe tendon pain and “cracking” or “popping joints” with immediate alleviation of pain during bouts of inflammation, some persistent over many months or with medication lessening to occasional flare points. Headaches that emanate from my neck are for me still one of the most debilitating of all symptoms of Ankylosing Spondylitis.

10 https://en.wikipedia.org/wiki/Tinnitus
8.0 Joint Pain

Lower lumbar pain to extreme, hip pain, sciatica, neck pain radiating into chest with “cracking” and spinal “crunching” only alleviated with hot showers, heat packs, anti-inflammatories and rest. My joints are almost always in some form of mild pain with pain centers increasing as the weather becomes colder.

9.0 Joint Locking

Sporadic, single joint and often isolated and recurrent small joint stiffening and locking as though the joint was filled with fluid and unable to bend. Associated pain is usually acute but short lasting - one week through to a month at a time. I have noticed that the joint locking effect is mostly during times of extreme inflammation rather than during lesser inflammation periods.

10.0 Immobility

During acute bouts of inflammation I have been rendered immobile with nausea, ringing ears, iritis and severe pain in the soles of my feet, hips, lower back and neck. During these times I have to sleep frequently and often will have broken sleep which has of late now been driving a diagnosis of anxiety, pain based apnea. My immobility is sometimes so acute I need to “roll” myself on a foam roller to alleviate the pain that radiates through my lower back, neck and chest.

11.0 Bloated Gut

During bouts of inflammation I note my gut is bloated and that I am more prone to gas buildup, pain and discomfort ranging from low grade general unease to full blown pain particularly after eating highly acidic foods, high yeast food types or food / drinks that are high in sugar. I note that my diet when high in low sugar, high carbohydrate, fresh fruit, fresh vegetables and broken into smaller meals leads to good results as far as a bloated gut is concerned.

12.0 Fungal Infections

When my inflammation levels are at their highest I note that my skin flora changes and that I suffer from a range of fungal infections probably due to the many and varied medications I’ve taken that strip vital gut flora. I attribute a bloated gut and dietary intake as commensurate to these symptoms and so a vigilance of dietary intake is needed in order to stay on top of these fungal infections.

13.0 Penile Pain

Final - 1st July, 2016
I have noted that penile function may be affected during times of high inflammation and whether this is related to vascular inflammation or simply due to concentrated urine, and combined medications.

14.0 Rectal Bleeding

I have often experienced rectal bleeding when I have had acute bouts of inflammation and where my gut is bloated. Again whether this is related to the myriad of medications, diet change or inflammation related to gut change is unknown. Generally this bleeding can last weeks or even months with a need for me to take large doses of vitamins due to blood loss.

15.0 Urinary Infection

I have noted urinary discolouration (with blood counts), differing smelling urine (medications) and general discomfort with urine passing increasing in frequency when my inflammation levels are high. I note that I often pass urine more often during the night than during the day whilst on NSAIDs which is a well known side effect.

16.0 Night Sweats

I may sometimes experience “night sweats” where I awake either mildly sweaty (beyond usual) to very noticeable where the bedsheets are noticeably damp. I also experience increased heart palpitations accompanying night sweats when I am on medications that are counteracting extreme pain (codeine based) or discomfort.

17.0 Iritis

Since 2002 I have been hospitalised twice with extreme cases of iritis affecting both my eyes which I was told I needed to be treated with Pred Forte\(^{11}\), Prednisolone\(^{12}\) and Sulfasalazine (Pyralin EN, Salazopyrin, Salazopyrin EN)\(^{13}\) which are all pretty nasty in isolation and combination.

In both cases I was admitted as a patient, isolated in a low light room and had eye drops put in my eyes on the hour every hour till my eyes were encrusted. In the first case I was hospitalised for 8 long days and nights.

\(^{11}\) https://www.drugs.com/cdi/pred-forte-drops.html
\(^{12}\) https://www.drugs.com/mtm/prednisolone.html
Salazopyrin is a sulphur based drug and the horse tablet sized medications made me feel “dry” and nauseous at times. Both my eyes have been damaged as a result of these attacks which lasted months and there have been noted ophthalmic “floaters” and other schema that now cloud my vision where as previously I had 20/20 vision. I feel like I have lived in a petri dish force fed every known drug doctors had on the shelf in order for their diagnostics to “stick” at times but of late I have come to understand my condition holistically and now have a better understanding on how to manage this condition in the long term.

18.0 Pulmonary Infections

Over the last 30 years I have had numerous pulmonary and/or lung related infections which have required asthmatic treatment and more recently corticosteroids14 Flixtotide and Becotide intervention. As a child I was a test case for the drug Intal15 (cromolyn sodium inhalation aerosol) and later Tilade, Alupent and Azmacort all discontinued in 2010.16

I still carry around with me a Ventolin17 inhaler although note that my asthmatic conditions are significantly reduced since I have all but eliminated cow's milk and now eat gluten free products. When my Ankylosing Spondylitis symptoms are at a peak I note my asthma returns. I am prone to lung infections in excessively dusty conditions, mouldy environments and I react to highly gaseous conditions brought on by air conditioning with allergies that affect my sinuses and ear, nose and throat passages.

All of them seem to irritate and inflame my sinus (nasal passages) A slight viral infection often shows up for me as a chesty wheeze escalating to a full blown cackling lack of oxygen due to phlegm and inflammation buildup.

I am often needing to take Xylometazoline Hydrochloride18 found in Rhinocort, Fess or Otrivine for allergic rhinitis to keep my nasal passages from blocking up. Having a deviated septum hasn't helped but I note that my chronic sinus related headaches are often occurring when there is few pathogens around yet at times when my general inflammation count is high.

19.0 Fainting

I was prone to fainting or syncope19 especially in my late teens during times when I was in pain with inflammation, in the heat and / or when I felt dehydrated as a result of the

14 https://en.wikipedia.org/wiki/Fluticasone_propionate
15 https://www.drugs.com/pro/intal.html
16 http://www.healthcentral.com/asthma/c/52325/109434/discontinued/
17 https://www.drugs.com/ventolin.html
18 https://www.medicines.org.uk/emc/medicine/20353
19 http://www.webmd.com/brain/understanding-fainting-basics
medication I was taking for the pain. I would often self medicate and over compensate by taking large doses of Nurofen Plus\textsuperscript{20} (containing codeine and Ibuprofen) during this period also which no doubt didn't help. In a number of cases I attribute the fainting to low blood pressure, anxiety and inflammation present at the time.

20.0 Bursitis

After tearing the meniscus in my left knee in 2007 I endured two arthroscopic\textsuperscript{21} knee operations in 2007 and 2008 to remove “large amounts of inflammatory” material. At the time I had extreme bursitis\textsuperscript{22} (my knee was almost 2.5 times normal size) and at the time I also had edema\textsuperscript{23} on the leg (fluid buildup).

Ankylosing Spondylitis in both cases caused the inflammation to get out of control and it took almost a year to resolve. In these cases I had to undergo surgery to have the inflammation sites removed and steroids to recover from the injury.

\textit{Photo - October 2007 and May 2008 arthroscopic knee operation}

\textsuperscript{20} https://www.drugs.com/uk/nurofen-plus-spc-10125.html
\textsuperscript{22} https://en.wikipedia.org/wiki/Bursitis
\textsuperscript{23} https://en.wikipedia.org/wiki/Edema
21.0 Pericarditis - Hospitalisation (Case One)

On New Year's Eve 2005 I collapsed whilst walking through Circular Quay in Sydney, hitting my head on a low brick wall and was taken to a local hospital by ambulance. During the ambulance trip I stopped breathing and my pulse non existent so cardiopulmonary resuscitation (CPR) was used to bring me back into the land of the living.

The ambulance officer then reverted to the use of defibrillators as CPR was initially not successful.

During that cardiac arrest I experienced being in a completely anxiety free space with bright light only returning back into myself when thoughts or memories of my children came into focus. At the time of the cardiac arrest I was intoxicated, had been dehydrated days before and had a chest infection causing me to feel like I had low oxygen count. I was also (stupidly) still smoking cigarettes at the time.

I was tested for the drug Ketamine\(^{24}\) upon admission which had been reported being used to spike the drinks of men in that area at that time. I was discharged 24 hours later after a CT scan\(^{25}\) and an ECG or electrocardiogram\(^{26}\) administered both in the ambulance and also on site at the hospital. I experienced an altered state of being (out of body experiences and vivid dream states) for almost a year after that experience.

The official diagnosis for that experience was pericarditis or inflammation of the pericardium. I wasn't discharged with any medications nor requested for follow through consultations probably due to the incredible pressure on that hospital at that time being New Year's Day.

I am seeking information under Freedom of Information for what happened prior to, during and after my stay at that hospital.

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\(^{24}\) [https://en.wikipedia.org/wiki/Ketamine](https://en.wikipedia.org/wiki/Ketamine)


22.0 Pericarditis - Hospitalisation (Case Two)

In early June 2016 I had been treated for recurrent iritis (under the broader spectrum of uveitis\textsuperscript{27}) which required me attending an eye clinic. I had presented at hospital with an extreme headache, lack of vision and they immediately gave me Cyclopentolate\textsuperscript{28}.

I was prescribed Pred Forte drops and discharged soon after. At the time I noted my urine had changed to a cloudy consistency and was stronger in odour but I put that down to not drinking enough water and the pain killers I'd been taking.

On Wednesday 22nd June 2016 I noted that a range of inflammation symptoms were at an extreme level - a chest infection, severe pain in my neck (which has been present for months), sweating in my sleep and ongoing iritis. I woke up covered in sweat, dizzy and with a chest pain extending from shoulder to shoulder and up into my throat.

I managed to stumble into the bathroom before feeling faint and nauseous. My partner (bless her) managed to catch me and lower me to the floor unharmed.

\textit{Photo - 2016 - Ambulance officer administering ECG}

\textsuperscript{27} https://en.wikipedia.org/wiki/Uveitis

\textsuperscript{28} https://www.drugs.com/cdi/cyclopentolate.html
I was sweating profusely and came around about 15 seconds later with extreme ringing (tinusitis) in the ears. I wasn't fully conscious and coherent for about ten minutes. An ambulance was called and the officers ran an ECG and my scan appeared to be normal.

They took me to hospital and ran a blood test that showed my heart enzymes blood level (enzyme creatine kinase (CK), and the proteins troponin I (TnI) and troponin T (TnT) ) to be 1800—a low count but suggesting either myocardial or pericardial arrest.29

I was given treatment for the former—liquid Aspirin30 and then shortly after I was administered a shot of Heparin31 in the gut. Almost immediately my body went into shock and arrest.

29 https://en.wikipedia.org/wiki/Cardiac_muscle
30 https://www.drugs.com/aspirin.html
31 https://www.drugs.com/heparin.html
My heart rate plummeted from 80 to less than 30 and I stopped breathing. I was administered a shot of Atropine sulfate\textsuperscript{32} and woke up shortly after in the hospital emergency resuscitation unit.

According to a number of medical practitioners I’ve consulted with there is known issues with administering Heparin on patients who have ankylosing spondylitis;

\textit{Pericarditis often occurs after a respiratory infection}. Chronic, or recurring pericarditis is usually the result of autoimmune disorders such as lupus, scleroderma and \textbf{rheumatoid arthritis}, disorders in which the body’s immune system makes antibodies that mistakenly attack the body’s tissues or cells.\textsuperscript{33}

It is also noted that medicines, like phenytoin (an anti seizure medicine), warfarin and \textbf{heparin} (blood-thinning medicines), and procainamide (a medicine to treat irregular heartbeats) may actually \textbf{cause or greatly enhance} the effects of pericardial arrest.

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{heparin_injection_site.png}
\caption{Heparin injection site one week later}
\end{figure}

After being taken to the coronary care ward in the hospital I was informed that I would be put on a saline drip and that I was to continue taking Aspirin. The following day I was taken

\textsuperscript{32} \url{https://en.wikipedia.org/wiki/Atropine}

\textsuperscript{33} \url{http://www.heart.org/HEARTORG/Conditions/More/What-is-Pericarditis_UCM_444931_Article.jsp#mainContent}
with great trepidation in for a full coronary angiogram\textsuperscript{34} which revealed I had no blocked arteries nor any heart tissue disease.

With great relief I was discharged with no further diagnostics either revealed from the ECG that was taken in the emergency resuscitation unit nor from any diagnostics that the on-call cardiologist could provide me. I note my “medical-in-confidence” report provided upon discharge states that I am female (not the last time I looked) and the fact that I would be discharged with Aspirin as the only medication to be administered with a followup visit to a cardiologist (the very same one who misdiagnosed me in the first place) in four weeks time.

My pathology report contains a record of all levels at average readings except for the presence of enzyme creatine kinase (\textit{CK}), and the proteins troponin I (TnI) and troponin T (TnT) which is typical of a heart under stress. No mention of heparin-induced thrombocytopenia\textsuperscript{35} treatment & management is mentioned in the report although this was the first aspect raised (HITS) by medical staff in the third place of consultation that week.

I am currently seeking all files in relation to my hospitalization under Freedom of Information to extenuate my knowledge of the condition, why I reacted to the medications administered and to ascertain whether there has been a case of malpractice during my hospitalisation.

\textsuperscript{34} https://en.wikipedia.org/wiki/Angiography
\textsuperscript{35} http://emedicine.medscape.com/article/1357846-treatment
23.0 Pericarditis - Hospitalisation (Case Three)

On discharge from hospital after the second case of pericarditis I decided to attend my local GP to report on the case and to get a script for Aspirin. I was feeling very low that day and had a huge pulse in my temples - like a pounding effect.

We decided to purchase an electronic blood pressure monitor at a local pharmacy and returned home to use it. I lay down and fell asleep for a few hours. On return my partner put the cuff on and we tested my blood pressure which returned with a reading of 159 (systolic) over 99 (diastolic) which indicates hypertension (stage 1). My neck pain was extreme (9 out of 10) and I had shallow breathing with a noticeable pain across my chest again.

Upon presenting at hospital triage yet again I was taken in immediately and an ECG was conducted which revealed no substantial results. My bloods were taken and the pathology report noted that my troponin levels were still elevated but down now at a count of 700.

I lay in the emergency unit all night whilst the on-call doctors mulled over my case. A short time later a smiling intern doctor returned saying that he believed I’d been treated incorrectly and asked a whole series of questions about my ankylosing spondylitis condition. Shortly after he returned saying he was going to send me to have a CT\(^{36}\) scan done of the heart and surrounding organs.

The CT scan did not provide any substantial results either and I was then taken through to the day care unit to rest away from the cacophony of the emergency department. They prescribed me the drug Meloxicam\(^{37}\) (Mobic) which I have taken before.

Within a few hours I could feel my chest pains subside, my neck pain subside and my coughing reduced. I was then informed that I would be taken through to the coronary care unit but isolated in a room that ran a full night time ECG over 8 hours to monitor blood pressure, respirations as well as heart conductivity.

By early morning I was discharged with only a ward nurse report which stated that no notable results from the overnight study despite the fact that the ‘apnea’ tag hovered over my statistics all night long.

\(^{36}\) https://en.wikipedia.org/wiki/CT_scan
\(^{37}\) https://www.drugs.com/meloxicam.html
I am currently seeking a comprehensive report from that hospital in order to update my personal file with my local GP and for my own records.

24.0 Sleep Apnea

During my recovery time at home my partner noted in the last few months that I had begun to snore during my sleep. To my knowledge I have never snored prior. It was also noted that I had a sever case of Restless Leg Syndrome (RLS) which woke me (and my partner) repeatedly during the night.

After these episodes of hospitalization I decided to attend a sleep clinic during which time the diagnostics revealed I have a deviated septum (80% blockage of one nostril) as well as elevated inflammation in the nasal passages and ears.

Questions of my partner reveal that I actually stop breathing sometimes (recurring) in my sleep and this causes me to wake in fright gasping for air. This I do know is happening during times when I have high levels of ankylosing spondylitis inflammation and is of great concern to me as I can consciously feel myself stopping breathing in an anxious state.
This whole extra dimension is known as obstructive sleep apnea\textsuperscript{38}

\begin{quote}
Due to the disruption in daytime cognitive state, behavioral effects may also be present. These can include moodiness, belligerence, as well as a decrease in attentiveness and energy. Another symptom may be sleep apnea is sleep paralysis, the fear of which can sometimes lead to insomnia. These effects may become intractable, leading to depression.\textsuperscript{39}
\end{quote}

I believe there are definitive links between my sleep issues and ankylosing spondylitis inflammation, that pain and sleeplessness due to pain end up up in a compound effect where sleeplessness, anxiety and inflammation are commensurate - not separate conditions.

I will be attending a sleep clinic soon which will provide me with a better idea of what the causal agency may be for apnea, or perhaps none at all. Whatever the case I know that good sleep, uninterrupted is critical to the recovery of the body to rest and to regenerate.

\begin{footnotes}
\item[38] https://en.wikipedia.org/wiki/Sleep_apnea
\item[39] https://en.wikipedia.org/wiki/Insomnia
\end{footnotes}
Conclusion

This paper provides a personal account of the core experiences which I have managed to live through for the last thirty years. The hypotheses that Ankylosing Spondylitis\(^{40}\) which causes inflammation and pain as a range of interconnected symptoms rather than separated conditions I posit as being critical in managing such symptoms.

As interconnected symptoms we can gain a holistic overview of entire schema rather than as western diagnostics often do just honing down on one aspect of the condition, ignoring interconnected presenting facts.

As this paper brings forward to consider, there are no known complete cures for ankylosing spondylitis yet, although there are literally thousands of medications and a plethora of ways in which they can be used or misused in combination used to manage this condition. All this equates to a question as to why western medicine continues to employ process orientations to manage a patient who presents with a debilitating condition with the singular medical discharge from the premise in mind.

Of course time spent, human resources and process expediency all factor in the manner in which a patient receives attention. Perhaps that is why the angiogram assistant whilst pushing the trolley towards the ward from surgery remarked to a passing staff member:

“....Hi ho, hi ho, it’s another one from the factory to go.”

Notwithstanding, despite the dystopia that this paper could otherwise paint for the reader there are fortunately as many holistic treatments for ankylosing spondylitis that I know for a fact work in conjunction with the anti inflammatory medication prescribed.

Here are seven things that I believe can make a substantial difference in managing ankylosing spondylitis both in the short term and longer term:

1. **Exercise** - by making a continuous and conscious effort to keep fit an ankylosing spondylitis condition is lessened in severity;
2. **Diet** - by avoiding high fat, high sugar and complex food types (lactose rich) the intestinal pathways to health are nourished and counteract medication effect;
3. **Sleep** - Returning to a reasonable circadian clock\(^{41}\) provides for pathways that the human body needs to regulate it’s own recovery;
4. **Circumspect** - treat all diagnosis from medical professionals as needing further review as they are often more unaware of your symptoms in unison;


5. **Antiinflammatory** - where possible treat the symptoms of ankylosing spondylitis with NSAIDs sparingly and avoid all pain killer short term medications;

6. **Commensurate management** - review your symptoms holistically rather than in isolation by researching and observing, noting and retaining for future review;

7. **Socialising (AS)** - by sharing your experience the symptoms of ankylosing spondylitis are better known, the connections open up new knowledge and you may just avoid repeating what others such as myself have discovered in isolation.

In conclusion, here is my plan for managing my ankylosing spondylitis condition:

- **Hydration** - drinking at least two litres of filtered water per day;
- **Tissue Salts** - taking tissues salts (Fer Phos, Kali Phos and Mag Phos.);
- **Stillness** - turning the computer off at 10:00 PM and doing very little till sleep;
- **Herbal Tea** - cut coffee out permanently and drink honey infused Camomile tea;
- **Passionflower** - take 5 drops with tea before sleep;
- **Vitamin B12** - take vitamin B12 to ensure I have adequate intake;
- **Food** - avoid high sugar foods; increase vegetables and fruit intake;
- **Anti Inflammatories** - low dose, specific and as required;
- **Exercise** - as often as possible to raise cardiac rates;
- **Research** - keep a close eye on medical and other alternatives to manage ankylosing spondylitis including the contentious drug Etanercept (Enbrel).
Bibliography


Questions and Answers about Ankylosing Spondylitis - NIAMS - Available at http://www.niams.nih.gov/health_info/ankylosing_spondylitis/


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