

AUTUMN 2011  
NEWSLETTER



# AStretch

ANKYLOSING SPONDYLITIS AUSTRALIA

[www.asaustralia.org](http://www.asaustralia.org)



## *The Concept of Non-radiographic Axial Spondyloarthritis by Dr Lionel Schachna, Austin Spondylitis Clinic, Melbourne*

*Non-radiographic axial spondyloarthritis* (SpA) is a term commonly used to describe individuals with symptoms of ankylosing spondylitis (AS) whose x-rays are normal. To obtain a diagnosis of AS, x-ray changes at the sacroiliac joints are required. As these x-ray changes can take 10 years or more to appear, most patients who develop AS will first present to a health care professional with *non-radiographic axial SpA*.

Up to 80% of individuals with *non-radiographic axial SpA* will have changes of inflammation seen on magnetic resonance imaging (MRI) scan. MRI is currently the best imaging method for the detection of active inflammation in the sacroiliac joints and the spine. The advent of MRI has been a major milestone in identifying patients early in the course of their disorder. In addition, an impressive reduction of active inflammation has been demonstrated in several trials treating AS patients with TNF blockers such as etanercept (Enbrel®), infliximab (Remicade®), adalimumab (Humira®), and golimumab (Simponi®).

The ASAS (Assessment of SpondyloArthritis) International Society has recently provided a definition for *axial SpA*. According to this definition, axial SpA occurs when either (i) abnormalities at the sacroiliac joints (either by x-ray or MRI) occur together with ONE or more features of SpA (such as inflammatory back pain, psoriasis or family history); or (ii) HLA-B27 (the gene that occurs in 85-90% of patients with AS) occurs together with TWO or more features of SpA.

In a study presented at the annual meeting of the American College of Rheumatology in November last year, researchers in the Netherlands evaluated 364 patients attending a general practice who had been experiencing chronic lower back pain symptoms for an average of nine years. Participants completed a questionnaire and underwent a full physical examination and blood testing for HLA-B27 and C-reactive protein. Using the ASAS criteria, the investigators diagnosed 77 participants (21.5 percent) with *axial SpA*. Of these, 52 were diagnosed using MRI with one other feature of SpA., 12 were diagnosed with a positive HLA-B27 test and two other SpA features, and 28 were diagnosed with X-ray with other feature of SpA. Overall, 6.6 percent of the participants were diagnosed with the more stringent diagnosis of AS. Compared to the currently accepted criteria of AS using conventional X-ray alone, the investigators found that three times as many patients were diagnosed with *non-radiographic axial SpA*. This study suggests that a greater number of individuals than previously recognised with chronic back pain in general practice could be helped early in their disease by referral to a rheumatologist.

The treatment of *non-radiographic axial SpA* depends on the severity of symptoms and current features of the disease. As with AS, the cornerstone of management remains physiotherapy and nonsteroidal anti-inflammatory drugs (NSAIDs). Disease-modifying antirheumatic drugs (DMARDs) such as sulfasalazine and methotrexate are generally only used to treat peripheral arthritis.

## Contents

The concept of non-radiographic axial spondyloarthritis by Dr Lionel Schachna	1
Understanding your pain by NASS	3
How a career change has benefited my AS by Warren	4
Anxiety and Pain by SAA	5
Slater's Greatest Test	7
AS Exercises by Margaret Lewington Physiotherapist	8
AS Group of Victoria Report by Annie McPherson	9
Queensland Report by Ross Wilson	11
How can you help survey	12
Calendar of Events	13

*The information contained in this newsletter should not take the place of advice and guidance from your own health-care providers.*

*Be sure to check with your doctor about changes in your treatment plan.*

## Contacts

AS Group of Queensland  
PO Box 193  
Taigum QLD 4018  
p: 07 3263 5216  
e: [qld@asaaustralia.org](mailto:qld@asaaustralia.org)

AS Group of Victoria  
PO Box 3166  
Burnley North VIC 3121  
03 9496 4045  
e: [belinda.martin@austin.org.au](mailto:belinda.martin@austin.org.au)

Continued from page 1

To date, three clinical studies with TNF blockers have been performed in patients with *non-radiographic axial SpA* showing a very good response in a high percentage of patients with disease duration of less than 3 years. In one trial, all patients discontinued treatment after 4 months of treatment with a TNF blocker. After a follow-up period of 6 months, only 40% had a flare of symptoms requiring recommencement of a TNF blocker. Among almost all AS patients treated with a TNF blocker, long-term treatment is required. The results of this study suggest that early short-term treatment with a TNF blocker may result in long-term remission of symptoms. These results are still preliminary.

In rheumatoid arthritis, MRI and ultrasound are more sensitive in detecting early changes indicative of inflammation and that ultimately precede changes detectable on plain x-rays. We have also adopted treatment strategies that move toward more aggressive treatment algorithms in rheumatoid arthritis during early "window of opportunity" to improve long term prognosis and potentially to decrease radiographic damage. Similar studies to understand the stages of AS have recently been performed and offer the promise of decreasing the risk of spinal fusion and stiffness with appropriate early commencement of treatment.

## Notice Board

### **Notice to all members in Toowoomba and on the Darling Downs**

*Any members interested in getting together for activities and fellowship in your area, please contact the AS Group of Queensland. We will connect interested people and you can take it from there. Our contact details are on the membership form on the back of the newsletter.*



### **ENTERTAINMENT BOOK 2011-12**

*Any members interested in buying an Entertainment Book, please contact Lynn at 07 3263 5216 or Email: [qld@asaaustralia.org](mailto:qld@asaaustralia.org)*



The brand new  
2011 | 2012  
Entertainment™ Books  
are now available.

*'Excerpts from the NASS website, reproduced with kind permission from NASS'.*

To find the full article, and lots more helpful information, go to

[www.nass.co.uk](http://www.nass.co.uk)

About AS - Managing my AS - Pain Management

Understanding the pain you are experiencing is one of the paths to relief. It is important to understand that, although you are in pain, you are not doing any physical harm to yourself. This is a crucial point for people with AS because the main form of treatment is exercise. Over the short term, exercise can sometimes increase the sensation of pain you are experiencing. However, over the long term, regular exercise will benefit you in terms of increased fitness, strength and mobility. All of these will reduce your experience of chronic pain.

## What is pain?

Pain is generally divided into two categories: acute and chronic

**Acute pain** is usually short-term, lasting anything from a few seconds to a few hours or a few days to a few weeks.

Acute pain acts as a warning signal that alerts you to possible injury. Some types of acute pain such as back strain or headache may be relieved without any medical treatment as the pain will ease off by itself. Other types of acute pain will be more serious, such as appendicitis, and will require swift medical attention to correct the problem and relieve the pain.

**Chronic pain**, is pain which occurs on most days and lasts for anything from 3 months to many years. AS is associated with the experience of chronic pain. In AS, the intensity of chronic pain varies within and between people. For example, many people report that they have good days where the pain is minimal, and 'flare up' days or weeks where the pain is at its most severe.

## Routes to pain management in AS

In AS pain is managed through a combination of painkilling [medication](#) and appropriate [exercise](#). Your first port of call

regarding medication is either your GP or your rheumatology team

## Pain management techniques

There are some pain management techniques that can help reduce the intensity of the pain you are experiencing.

## Learning to relax

Learning to relax is something that everyone can benefit from. The feeling of being relaxed and calm can benefit many aspects of life including; sleep, concentrating on complex tasks and reducing tension and stress. If you are in pain, relaxation is even more important. Pain can often result in a lot of muscle tension. The more tense you are the more likely you will feel the pain getting worse. Learning to relax can help reduce tension and help stop pain getting worse. Pain can often make you feel upset, anxious and helpless and consequently make it harder to manage the pain. Learning to relax will help you feel more calm and in control regardless of the pain.

Pain can affect your ability to sleep. Learning to relax can help you get to sleep and make it easier to get back to sleep if your pain wakes you.

Breathing correctly is a vital part of relaxation. The aim of breathing correctly is to fill your lungs with air as effectively as possible. As you breathe in a muscle called the diaphragm should push your tummy out allowing your lungs to expand and collect all the air.

### *Remember:*

Learning to relax is a skill and like any other skill it requires some practice to get it right. So be patient with yourself.

Try practicing these techniques every day and you will soon notice that you are getting better and better. Eventually you should be able to do these techniques anywhere that you need to; on a bus, in the office or when you are walking.

## Pain distraction techniques

Distraction techniques can be a useful way to help you cope with your pain. They don't take away the pain completely but can help take the edge off it. At the very least distraction techniques can help you take your mind off the pain. The more senses you use whilst practicing these techniques the easier you will find it to block out the pain signals.

### *Taking your mind away from the pain*

Close your eyes and think of a pleasant, happy or relaxing scene. Maybe you are in your garden on a warm sunny day or on a beach on a tropical island. Now imagine that you are really there and focus on the detail.

## Focusing on the pain

Imagine that you can see your pain from a great distance away. Do not think about how much it hurts but just focus on describing it to yourself. What are the sensations, where are they coming from? It is almost as if you are observing the pain from someone else's body. Try not to get upset about the pain. Instead try and describe it as if it does not belong to you. This technique can be helpful whilst practicing your relaxation.

*Taking on a fresh and clean look the new NASS website was launched in December 2010. Aimed at following a patient's journey with AS the new website has a wealth of information from pre-diagnosis through to managing and living with AS. The new website also hosts a new section highlighting the importance of exercise for people with AS with information and a range of materials to exercise at home or in the gym. This links nicely through to the new NASS Near You section which has a page for each NASS branch offering regular hydrotherapy and physiotherapy sessions. There is also a revamped research area with current research programmes as well as a preview of recently published papers in AS. These sections and more can be found at [www.nass.co.uk](http://www.nass.co.uk). You can also keep up to date with news and events at NASS by signing up to our new regular e-newsletters.*

## How a career change has benefited my AS by Warren

As an employee of a number of major banks since finishing year 12 in 1980, I have spent almost 30 of my 48 years sitting behind a desk. Until my diagnosis with AS in 2000 I really didn't give it much thought, but after talking to members of the Qld AS group and my rheumatologist, I started to realise I really was not in the best occupation for my condition, basically by being sedentary 8 hours a day 5 days a week.

From 2000 to late 2004 I regularly attended Margaret Lewington's hydro class in Brisbane which was the best thing I ever did. I was feeling great. When the opportunity arose for me to move to Sydney with the bank, I jumped at it as I was feeling good and felt I could physically cope with the move back "home" (born in Sydney but had not lived there since 1988).

As there was not a lot of AS support in Sydney, I found the closest heated pool to home and would go once or twice a week after work to do my exercises that were indelibly inked into my brain from nearly 5 years of hydro classes with Marg. Even though I could not do them all, I could do around 60% of them. This kept me pretty good for a while but I was still experiencing semi regular flares. Funnily enough these flares were usually around the change in seasons which would last around 3 to 4 days and I also had general stiffness in mornings and evenings but now also with pain beginning in my feet and hands which no amount of exercise helped.

After 4 years back in Sydney we felt it was time to move back to Brisbane where we realised we wanted to be. I also wanted to make the move back before I was in a situation where I felt I physically couldn't face a big move interstate and we would end up having to stay there. (the pain in my hands and feet was really starting to get me down). I requested a transfer back to Brisbane which was approved and we made the huge move back. (If you saw our house and our love of potted plants you would understand what "huge" means).

My move back co-incided with major changes in my workplace that meant added stress and longer hours. Here was me thinking I was coming home to the

Qld AS group and the hydro classes I had missed so much, however due to work commitments I could never make it to the class and I slowly got into a rut of going to work and going home and basically doing no exercise. The more pain I got the more I felt sorry for myself and I knew I really needed to snap out of it and do something positive.

My GP and Rheumatologist urged me to exercise and "fit it into my daily routine, not add it on" as I think they knew I just wouldn't fit it in any other way. I started to park the car at Southbank and walk over to the city each day so I was at least getting 20 minutes walking each way every day. This did help but my work situation just left me depressed and still in my same old rut. As banking was all I had ever done, and I was in a major comfort zone, I think I came to believe that this would be my lot in life.

I believed I would not be capable of doing a more physical role as my frequent flare ups would prohibit this, and I thought as long as I could get to the office, I could sit there all day and function efficiently in my job, even though in my heart I knew I was getting stiffer and having more frequent flares.

In August 2010 the area of the bank I worked in was centralised to Sydney (how ironic) and I was retrenched. Ok I thought, this is my time to make some big changes in my life and the first thing I did was to start back at the Hydro classes with Marg each week. Immediately, psychologically I felt better as I knew I was now doing something positive again.

After many job applications and interviews with different financial institutions, I knew banking was no longer for me. I had no enthusiasm looking for banking roles and knew I would end up back where I was in regard to my health, so I bit the bullet and changed careers in a big way.

I became a Personal Carer for people with disabilities. In the back of my mind I was so worried my back / hips wouldn't cope but I thought why not give it a go, in three months or so if it doesn't work out I can go back to banking.

I have now been a Carer for 3 months and so far so good. I have had NO flares since I started. Of course I get a bit achy in my lower back as I am on my feet basically 8 hours of the day moving around and being active - nothing that a couple of Panamax does not fix. No longer am I as stiff every night after work or in the mornings. The physical activity of my new job plus my weekly hydro class has been so beneficial you would not believe.

As an added bonus, I visited my rheumatologist this past week and he compared my blood test of that week with one 4 months ago. To his amazement, the inflammation levels in my blood had HALVED. The only change in my life in that 4 month period was leaving a sedentary job, going back to the Hydro class and starting in a more physically active role.

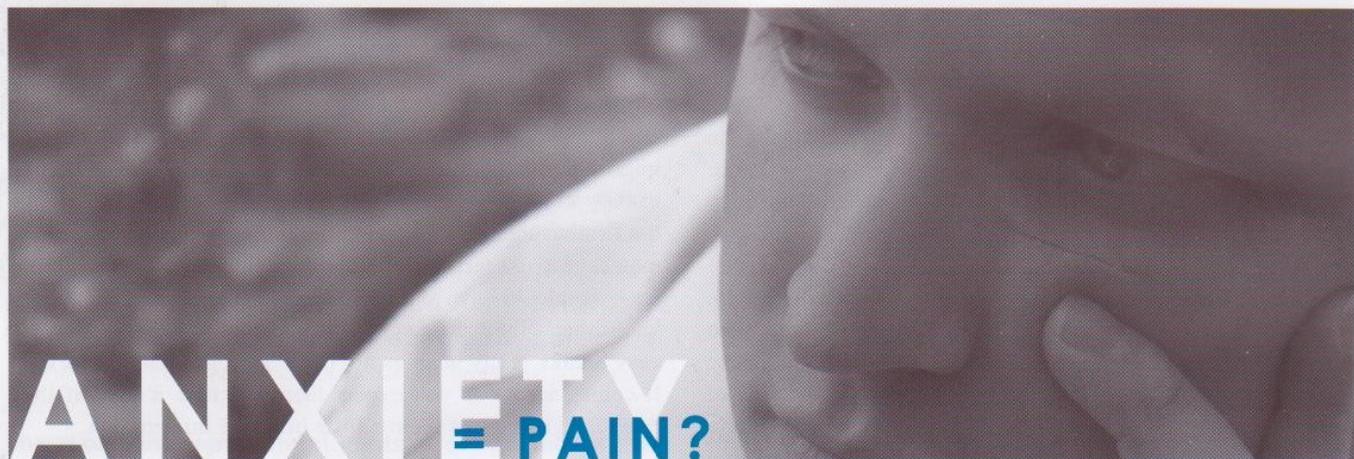
I still take one Celebrex daily as I have done for many years now and I have been on a very low dose of Methatrexate for around 2 years which keeps the pain in my hands and feet at bay.

The moral of this story.....

*whatever happens in your life don't let anything get in the way of your attendance at the hydrotherapy classes (or at least regular exercise) and just as important, don't let physical activity scare you as it just may pay off as it has done so far for me.*

Cheers

Warren  
Brisbane



# ANXIETY = PAIN?

**C**hronic pain and inflammation, like that associated with ankylosing spondylitis, can be related to anxiety. In fact, a study conducted in 17 countries around the globe found that people with chronic neck and back pain were more than two times more likely to develop an anxiety disorder than those without neck and back pain.

But what is the connection between anxiety and pain . . . and what can we do about it?

Anxiety, says Ron Glassman, PhD, MPH, a New Jersey-based behaviorist and neuroscientist who specializes in anxiety, fear and phobias, is a surge in stress hormone levels in the blood stream. When this surge occurs (adrenaline is the primary stress hormone involved), our fight-or-flight response is initiated. Our heart rate increases, our muscles tense up, our palms become sweaty. This fundamental physiologic response is our body's primitive, inborn reaction that prepares us to either fight or flee from perceived harm. That harm can be physical—such as a man running at you with a knife; mental—such as worrying about how you're going to pay the bills; or medical—such as dealing with the dull, throbbing pain that accompanies a disorder like AS.

### Stressed-out cells

The more stress our body is under, the more distress it causes to cells in the body. Our bodies are comprised of billions of cells. Stressed cells lead

to inflammation, and inflammation oftentimes leads to pain. Anything that ends in "itis" is inflammation—appendicitis, sinusitis, spondylitis.

"Anything that causes our body to be out of balance puts stress on cells," says Dr. Glassman. "Inflammation is the body's response to stress. Inflammation is to the human body what rust is to lawn furniture—it wears it down."

Individuals with spondylitis know the effects of inflammation all too well: persistent pain and stiffness spreading up the spine and into the neck; tenderness in the ribs, shoulders, hips, knees, thighs and heels; and fatigue as the body expends energy to deal with the inflammation.

Stress and anxiety exacerbate the inflammation associated with AS (just as they exacerbate many other illnesses, even the common cold). While the inflammation will likely never go away, there are steps individuals can take to reduce their stress levels and improve their quality of life.

The traditional Western approach to coping with stress starts with medications like relaxants (Xanax) and antidepressants (Zoloft). These medications are effective for most people, but they do have side effects. General day-to-day anxiety, considered mild to moderate, is often best managed without medications by learning stress management techniques. Dr. Glassman's approach to anxiety and stress management is based, in part, on the Relaxation Response, which has its roots in the East.

### Five minutes to calm

Based on Transcendental Meditation, the Relaxation Response is a form of meditation that has been practiced for many years. Herbert Benson, MD, the founder of the Mind/Body Medical Institute in Boston who defined the Relaxation Response, says the Relaxation Response "is a physical state of deep rest that changes the physical and emotional response to stress and is the opposite of the fight-or-flight response."

The benefits of the Relaxation Response are an increased awareness of whether you are tense or relaxed and a greater ability to relax when you are stressed out. Dr. Glassman says practicing his modified version of the Relaxation Response three times a day for five minutes can create a greater level of balance in the body, reducing inflammation and pain.

#### Here's how it's done:

- Sit in a chair or recline on a couch or bed. A quiet space is better, but not necessary. Close your eyes and take a half-dozen or so deep, cleansing breaths to get oxygen into your bloodstream. Dr. Glassman says these cleansing breaths help release the “steam valve” created by stress, increase feel-good endorphins, and decrease stress hormones.

- After completing the cleansing breaths, think about each major muscle group from your head to your toes. Tighten your face and jaw muscles, hold them for 3 seconds, then relax. Then, move to your shoulders. Raise and hold them for 3 seconds, then drop them like lead. Tighten your arm muscles, count to 3, and let your arms go limp. Continue doing this with each major muscle group right down to your feet. “In order to feel what muscles feel like relaxed,” says Dr. Glassman, “you must first tense them up. This helps you to recognize when you’re tense and understand true relaxation.”

- Visualize a situation in your mind that you associate with feeling good. For some, this may be standing on a beach, while others may find comfort on a mountaintop. Daydream about this situation and let your body and brain absorb the feeling. “There’s a direct connection between how we think and how we feel,” says Dr. Glassman. “The visualization of this feel-good situation sends calm into your body.”

#### Seduce your mind

Regardless of your medical condition, says Dr. Glassman, if you have chronic pain, this approach is where you can “seduce your mind to decrease your pain intensity. You can use your mind to improve your condition.”

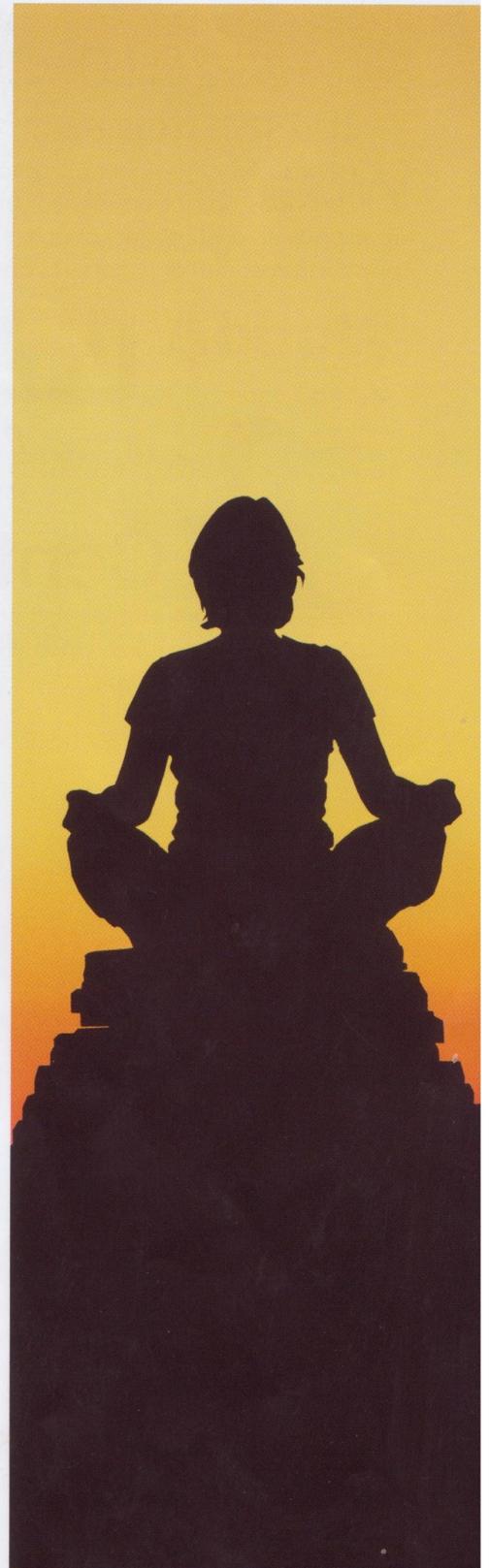
About 20 percent of the patients Dr. Glassman treats have spondylitis. He says that those who practice his modified Relaxation Response diligently—three times a day for a solid month—report less discomfort and feel as if they are a part of their disease resolution.

*“Stress and anxiety exacerbate the inflammation associated with AS (just as they exacerbate many other illnesses, even the common cold).”*

“It’s empowering to 100 percent of the people who try it,” he adds. “One hundred percent feel less discomfort. Their pain is not gone, but it’s less frequent, less intense.”

In today’s busy world, we can’t stop stress from happening. Stress hormones are constantly flowing because many of us are always under the gun. For individuals with spondylitis, stress and anxiety only add to the pain and discomfort they may already be feeling. But, if they can train their mind and body to be more resilient to stress [through the Relaxation Response], then they are less likely to feel that racing heart and sweaty palms—and their pain and discomfort might just go away for awhile, too.

*SAA would like to thank Dr. Glassman for his contribution to this article.*



(Reproduced with thanks from a winter 2010 edition of SPONDYLITIS PLUS News, the newsletter for Spondylitis Association of America (SAA))

# Slater's Greatest Test

## Physiotherapists back Arthritis Australia's quest to raise awareness of ankylosing spondylitis

With the Australian Physiotherapy Association (APA), the Australian Rheumatology Association (ARA) and Arthritis Australia (AA) all banding together, it is hard to ignore their warnings about the spinal health of Aussie blokes.

Cricketing legend **Michael Slater** knows all too well the impact of back pain – he suffers from a severe spinal condition known as ankylosing spondylitis (AS). Slater joins the organisations to raise awareness of AS – a condition that affects **three times as many men than women**.

AS is a chronic autoimmune disease and a form of arthritis that primarily affects the spine, although other joints can be affected. It causes inflammation of the spinal joints (vertebrae) that can lead to chronic pain and discomfort, and in severe cases can cause the spine to fuse.

“For 20 years I’ve lived with brutal back pain, which at times felt like a knife was being run down my spine – it nearly cost me my cricketing career. If I didn’t get the right help all those years ago, my condition would have fused my spine together and who knows where I would be today,” says Slater.

## New resource for AS sufferers

In a bid to urge men with persistent back pain to seek professional help, Slater has teamed up with physios **Margaret Lewington** and **Tony Morley**.

The three have recently filmed an **AS exercise video** to assist people with the condition alleviate some of the symptoms. The video will soon feature on the **Arthritis Australia website** and **You Tube** page.

The video is a part of Arthritis Australia’s campaign to raise awareness of the condition.



Currently, as many as 200,000 Australians have been diagnosed with AS. Morley, who suffers from AS himself suggests there is also the possibility that this number could be much higher due to the many men who may not have been diagnosed.

The President of the Australian Rheumatology Association also weighs in. Dr Louis McGuigan says for many Aussie men, their pain could be much more than a ‘bad back’ and without proper diagnosis could have serious consequences.

## Social and emotional impact

Not only does AS and back pain challenge pain thresholds, but a recent survey by Arthritis Australia reveals the spinal health of Aussie blokes is ricocheting into all aspects of their lives.

Of the 2.3 million Australian men who were found to suffer from persistent back pain, depression rates soared to double that of the general male population. Additionally one-in-four fathers are also forced to miss out on play-time with their kids, and partners are left to cope with disrupted sleep and mood swings.

Slater is a testament to the importance of recognising symptoms, seeking help and receiving the appropriate treatment. “Although I’m getting older, I’m still able to get down on the floor with my kids, which would have been a major issue 15 years ago.”

Dr McGuigan acknowledges Slater was smart in seeking help early. “He can now control his condition rather than it controlling him. It is imperative anyone with persistent back pain sees a GP and asks if they need a referral to a rheumatologist.”

**For further information on AS, visit Arthritis Australia:**  
[www.arthritisaustralia.com.au](http://www.arthritisaustralia.com.au).



Tony Morley, Michael Slater and Margaret Lewington at the filming of the AS exercise video.

# AS Exercises

By Margaret Lewington  
Physiotherapist

The theme for the exercises for this newsletter is to lie on your back and we will aim to increase rotation in the low back and the hips, mainly.

## 1. Knee rocking

Lie on your back, with your knees bent and feet flat. Place your arms out to the sides, palms up – to open the front of your chest and shoulders –



Rock both knees from side to side. Take as far as possible to each side, trying to get

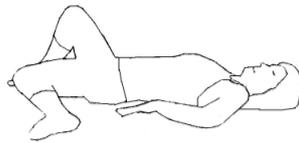
your knees to the floor. Keep your shoulders on the floor. You may like to turn your head to the opposite side. You can try it with your arms in various positions – by your side, clasped behind your head, level with your shoulders or above your head and moving from side to side as you turn your head.

Now take your feet wider apart. Roll from side to side again, as above, but this time the top leg will drop inwards towards the floor. Take it as far as you can -it may drop



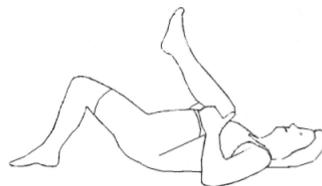
down to touch the floor. You should feel more stretch along the outside of this thigh and also let your back arch a little more.

## 2 Single knee rock

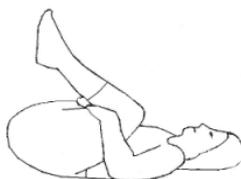


Lie on your back, knees bent, feet flat and wide apart. Drop one knee inwards as far as possible, keeping the other knee steady, and then up and drop outwards. Repeat several times and then change legs, or alternate legs, as you prefer. Try and get as much movement in the hip as possible. Watch that you are not tricking with back arching.

## 3. Knee to chest



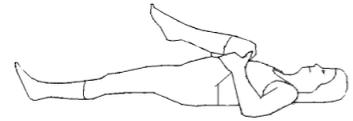
**SINGLE** -Lie on your back, knees bent up, feet flat. Bring one knee to your chest – holding behind your thigh to avoid strain on the knee. Feel your back round and stretch. You may even like to rock this knee up and down, feeling your back roll on the floor. Change to the other leg.



**DOUBLE** –Now bring both knees to your chest and repeat as above.

## 4. Knee to chest – with alternate hip stretch

Lie on your back with your legs straight. Bring one knee to your chest, as above, but keep your



other leg out straight and as much of the back of the thigh on the floor as possible. Feel a stretch in the front of the hip of the straight leg. Make this a longer stretch without rocking. Repeat with the other leg.

## 5. Knee rock in the tuck position.

Bring both knees up onto your chest. Roll both knees from side

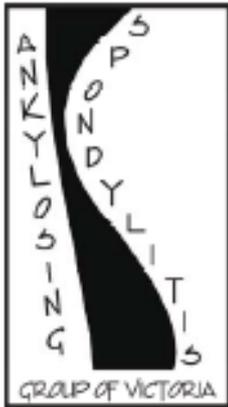


to side. Gradually make this movement as big as possible. Keep your arms out to the sides, palms up and shoulders on the floor.

## 6. Trunk rotation roll.

Lie on your back with your legs straight. Bend one knee up to your chest and then take it over your body to the other side. Aim to let your toe, and maybe your knee, touch the floor beside you. Your leg can straighten a little to a comfortable angle. Feel the rotation in your low back. Lift it up and back down. Repeat with the other leg to the other side.





As we move into the New Year, we nearly always have a selection of new and challenging times ahead. This year I am trying to come up with new ideas for exercise for both mind and body to keep active and alert (yes I know very ambitious). Coincidentally, I

was able to make a start on both activities in Bendigo, country Victoria this February. I wished to visit my sister Heather, to see how her garden had fared after the pro-longed drought and then more recent summer rains. Heather is our family "star gardener" and if she can get a plant to grow in Bendigo it will grow almost anywhere. As a result, Heather and I have planned some new projects for my seaside garden, which is a constant battle with the elements and wildlife.

Gardening is such a mentally relaxing activity, even if one has to invent the most odd-looking methods to avoid bugs, snakes, sunstroke and just plain over-doing-it.

The second reason for visiting Bendigo at this time, was to attend a new Arthritis Victoria "Get Active" workshop program, to help inspire my physical exercise program. I have explained more on this event in the Arthritis Victoria section below.

## AUSTRAL HOTEL - ANNUAL AUTUMN DINNER

KORUMBURRA – FEBRUARY 2011  
A group of country folk and a few city-dwellers, 17 people in total, met for lunch at the Austral Hotel in central Korumburra, Gippsland on a Saturday in late February. The date was chosen, as we were in-between the summer holidays and the beginning of football seasons. We had a strong contingent from Ellen's family and were pleased to have Vic and Valmai join us with Vic doing so well. We also had the company of a new member Jon, who has recently moved with his family to Australia from the UK. All enjoyed the good ample lunch servings and

the children enjoyed their Aussie fish and chips. Jon's youngest, Tom won the drawing/colouring competition with Ellen a close second. During the lunch, a number of members were able to discuss their new medication treatment programs and how it helps them manage their condition on a daily basis. The dining room was very quite on the day and we were able to have a large roomy section to ourselves. The trip, from the city and Mornington Peninsular, was around one hour, quite good for Saturday morning traffic. Of course the country folks had it easy for the event, with around 15 minute on average for their trip.

## JOINT WALK YARRA BEND /STUDLEY PARK – March 2011

Our next event, our annual Joint Walk in Yarra Bend, coincides with Arthritis Awareness week in late March, and by the time this newsletter goes to press, we will most likely have enjoyed our walk on Sunday 27 March. This year we are returning to Yarra Bend (opposite Studley Park) to walk around the bush and perhaps visit the Studley Park Boathouse kiosk [excellent ice-creams] over the footbridge. We enjoy being outdoors when Melbourne's weather permits and we do not have to layer up against the cold. We hope you can join us for some fresh air and a long stretch.

## TREASURER'S RETIREMENT

At our recent AS Group of Victoria committee meeting, our talented treasurer, Rosemary McRae tendered her resignation, due to the wonderful news of her move to the leafy Melbourne suburb of Hurstbridge and "new" home with husband Richard.

When we established the Ankylosing Spondylitis Group of Victoria in May 2005, Rosemary joined us as a founding committee member and treasurer and took care of all our financial matters. Over recent years her role has expanded considerably to include membership processing and correspondence, grant applications and affiliated association correspondence. Rosemary's contribution and expertise will be sadly missed on our committee as will the enormous effort she offered on behalf of the group.

On behalf of the committee and the many friends she has made in our group, we all wish her happiness and prosperity in this new environment.

*[Look for a further in-depth interview with Rosemary in a future edition of AS-tretch]*

Our committee has asked our long standing volunteer, Maria Makris, to stand in as acting-treasurer until our elections in May/June this year. If you would like to volunteer on the committee or stand for an office-bearing role, please contact me as soon as possible and we would be happy to discuss matters as we have several vacancies.

## ARTHRITIS VICTORIA UP- DATE

The year commenced with the introduction of the new Chief Executive Officer Linda Martin, appointed at Arthritis Victoria (Arth.Vic) in December 2010. Linda has replaced Natalie Savin who served for over seven years in this role, leading the organisation into a more "consumer" focused group. Linda's recent background includes time with a management consultancy and training group, and prior to this she had extensive experience in community services and public health.

Our February and March meetings of the Consumer Advisory Committee and the Research Advisory Panel included topics outlined below:

At the Arth.Vic Geelong Regional Seminar, October 2010, the **Beyond Blue organisation** gave an interesting presentation on **managing depression and anxiety**. Comments from the attendees indicated it would be beneficial to have this team present a specifically tailored talk for those living with a musculoskeletal condition. As we have previously noted Arth.Vic also has representative on the research project "Stepping Up"- when arthritis gets you down; an online self-management tool currently being developed to address this area.

*[Please also refer to the article earlier in this publication, "Pain and Anxiety"]*

During November 2010, the Monash research team presented their poster and

report results to the (Arth.Vic) Advocacy and Research team on the joint project **Workplace issues of people living with Arthritis**. Some of our Victorian members may recall contributing to this survey during the middle of 2010 and these reports are available for those interested in the project. The Young Adults annual seminar "All Fired-Up" in November 2010 included a presentation by the legal firm Maurice Blackburn Lawyers on these issues. The Arth.Vic Training and Education team have decided to further pursue this subject in their "Your Rights at Work" seminar planned for this year.

In addition, as part of research for a new member, we have found a national government Centrelink agency who specialise in employment services for those with disabilities who may wish to return to the workforce.

Refer to the Centrelink web site for details and information:

[www.centrelink.gov.au](http://www.centrelink.gov.au)

Or call Centrelink on 13 27 17 or CRS Australia on 1800 277 277 for further information.

**Women with Disabilities Victoria** prepared a paper and submitted it at the May 2010 Australian Women's Health Network Conference, Hobart. Included in the paper is a number of health screening program issues relating to difficulties for women with disabilities. In addition, **BreastScreen Victoria** has agreed to up-

date their policy in this area. Please contact me for details, if you have an interest in this area.

In February I attended the **Get Active workshop** program in Bendigo where trained Arth.Vic health educators covered the benefits of exercise, services available in the community, how to get started and stay motivated. This program was easy to follow and generated plenty of discussion on the types of activities available in the community.

### 2011 CALENDAR OF COMMUNITY PROGRAMS AND ACTIVITIES

In February Arth.Vic released their calendar of Community programs [seminars], education, training, and exercise activities for 2011. The calendar includes country and regional seminars, interactive workshops with exercise, dealing with change and your rights at work, self management programs, better health, osteoarthritis and rheumatoid arthritis programs. Please check the Arthritis Victoria web site for details of the programs.

In **Arthritis Awareness week starting 27 March 2011**, Arth.Vic will be launching their "Arthritis Victoria Map" at RMIT University in Melbourne. This interactive online map has been developed to display information from across Victoria: Prevalence of musculoskeletal conditions; Specialist and primary health services; Disability-accessible community facilities;

Physical activity programs (like water exercises) and health planning data. This project was initiated as a direct result of issues raised in the Consumer Advisory Committee discussions on the lack of access people have to programs and services in country Victoria. We will continue to report on the outcomes of areas of interest and subsequent projects throughout the year.

**Arth.Vic Consumer Conference, Saturday 02 April 2011**, the annual Consumer Conference is to be held in the William Angliss Institute, Melbourne central business district. Presenters include Rheumatologists, Physiotherapist, Dietician, and Psychologist. Some of the sessions are based on an interact format and an exhibition area is planned for related suppliers and services.

**Please contact Arthritis Victoria for programs and seminars in your area, on 8531 8000 or 1800 011 041.**

## Hydrotherapy in Western Australia (Perth)

**WHERE:** Royal Perth Rehabilitation Hospital  
Shenton Park Annex Selby St Shenton Park

**WHEN** Every Monday evening  
(Public Holidays excepted)

**COST** \$ 7.00

**PHONE** 08 9382 7307 Lindsay

### TIMES:

Hydrotherapy Pool  
5.30pm Hydrotherapy exercises

Gymnasium  
5.45pm - Land Exercises

*Note: All sessions are conducted by experienced Physiotherapists. Total Session time is two hours with groups changing over at the end of the first hour.*

*Also: Another AS/spinal mobility Pool Class is available at South Care, St John of God Hospital - for details: 08 9366 1730*

After a wet and wild start to the year everything is slowly getting back to normal. Our thoughts go out to those impacted by the floods and cyclone and hope everyone is safe and well. Our Hydrotherapy class at the Royal Brisbane Hospital had to be cancelled the week of the floods due to the surrounding streets going under, but was back to normal the following week.



After many weekends of rain we were lucky to have a beautiful fine evening for our dinner and bridge walk. After sitting down to some very generous serves of fish and chips etc. at Tingalpa we made the short drive to the Gateway Bridge. The weather couldn't have been any better for a leisurely stroll over the bridge and back (approximately six kilometres).

For those who do not know the Gateway Bridge, the new bridge has been designed with a lovely wide and well lit walkway for pedestrian and cyclists. It also has a number of viewing areas with shaded seats and water fountains for those who would like to rest along the way. To finish off the night we enjoyed coffee and ice creams at the local Maccas and everyone agreed it was great to combine dinner and exercise.



It was wonderful to welcome some new faces to this event. The events/activities are definitely worth the effort, so please consider attending one of our future events.

We will definitely have something similar later in the year; this time maybe a river walk once all of the repair work from the floods have been finished.

Remember to check your emails, the AS website and the Newsletter social calendar section for any upcoming events.

If you are looking for information on the net, I can recommend the NASS site, which is the English AS Society, who have just updated their site, and it is well worth a look.

As the winter months approach and the weather gets cooler, try and continue your exercise routine, as it will definitely benefit you in the long run.

Till next issue,  
Ross Wilson



# “How Can You Help”

The AS International Federation of which we are a member is conducting an online survey as part of a project they are undertaking. I urge you all to take the time to read the following article and take part in the survey. The survey can be found at:

<https://asif.any-survey.com/>



**Bed-it!**



*This heading should not be understood as a call on our members to put this away and go to bed! Indeed not! On the contrary, it should serve as inspiration for you to participate in an upcoming questionnaire survey to investigate if we as AS patients experience general problems in connection with overnight hotel stays.*

By Susanne Gøttiske & Seoirse Smith (ASIF President)

The background is a member's inquiry to the Danish AS association as to whether they had a list of hotels with beds, pillows, etc. which are appropriate for AS patients. Finding hotels with good beds was a problem for him as he traveled a lot and had many overnight hotel stays domestically as well as abroad.

Unfortunately, they do not have such a list of hotels which they could recommend members to use but it caused the executive committee to discuss how big this problem is in general for AS patients with somewhat stiff joints in oblique angles. We all know how important it is to us all to get a good night's sleep, particularly if we have work-related overnight hotel stays.

Many of us know of hotels where the pillows in the beds are big, firm, and foam-filled. It is an impressive sight when the beds are made but such pillows are hardly comfortable to rest on. And worst of it all is probably that folding, pushing or nudging the pillows does not help to shape them comfortably for AS patients.

If the AS patient's neck is not perfectly stiff at bedtime, it certainly will be in the morning after a night on a pillow like that.

ASIF, hopefully with the co-operation of all national associations, with financial support to the project from Abbott, have decided to investigate the extent of the problem/problems for AS patients. If the problem is big and general, it is the intention to try to encourage/inspire hotels all over the world to have some "arthritis-friendly" rooms available, and smaller hotels to have some AS-friendly pillows and/or mattresses available for people like us.

In the first place, we will attempt to find out whether there are problems and, if so, to which extent. Identical questionnaires/surveys will be presented to the member associations to circulate to their members in order to get an overview of what the extent might be. The data from the survey will be the basis for the decision as to whether we will continue the project or not.

We encourage all our members to fill in the questionnaire, whether you have problems with overnight hotel stays or not, in order for us to get a picture, that is as realistic as possible, of the potential problems.

**The questionnaire/survey can be completed online at:** <https://asif.any-survey.com/>

Please help us collect data on the extent of the problem by completing this survey as soon as possible. Once the result of the survey is available, you will of course receive feedback with thanks for your assistance. The spin-off of this sort of project, assuming it goes ahead of course, is that an increased level of awareness of our condition is generated



## Calendar of Events

### Victoria

Vic AGM at Austin Hospital mid June further detail to be advised.

### Queensland

Saturday 18<sup>th</sup> June 7pm Dinner at Neo's Pizza and Pasta Restaurant, Gladstone Rd., Highgate Hill.

## General Information on the web

### **Spondylitis Association of America**

[www.spondylitis.org](http://www.spondylitis.org)

Contains message boards, online chat forums, and a members only section for resources.

### **The National Ankylosing Spondylitis Society (NASS) (United Kingdom)**

[www.nass.co.uk](http://www.nass.co.uk)

Contains an excellent questions and answers section and downloadable guidebook-A Positive Response to Ankylosing Spondylitis-Answer and practical advice.

### **Ankylosing Spondylitis International Federation (ASIF)**

[www.spondylitis-international.org](http://www.spondylitis-international.org)

### **Arthritis Australia**

[www.arthritisaustralia.com](http://www.arthritisaustralia.com)

## Hydrotherapy in Brisbane

Supervised by Margaret Lewington

(B.Phty. Cert Hydro)

**WHEN:** Tuesday Nights

**TIME:** 6.30 - 7.30 pm

**WHERE:** Hydrotherapy Pool,  
lvl 2, Ned Hanlon Building,  
Royal Brisbane & Women's  
Hospital, Butterfield St  
Herston.

**COST:** \$10 or 10 classes for \$90

**ENQUIRIES:**

Margaret 0404 414 501  
or 07 3376 6889



# A.S. GROUP OF QUEENSLAND



## Ankylosing Spondylitis Group of Queensland Membership Application Form

The AS Group of Queensland provides information and support to people living with AS and also their partners, families & friends & the wider community by:

- Encouraging each person to take responsibility for his/her health
- Facilitating the provision of exercise programs, classes and educational workshops
- Providing opportunities to meet
- Encouraging research into the cause, management and prevention of AS
- Provision of a regular (quarterly) newsletter covering the latest local, national & international AS news.
- New members receive a complimentary copy of AS land exercise DVD (please tick box below to receive)

New Member       Complimentary DVD       Renewal      Date.....

Name:.....

Address:.....

.....post code.....

Telephone:.....

Email:.....

### MEMBERSHIP TYPE

Full (Newsletter by mail) (\$20.00) .....

E-mail (Newsletter by email) (\$15.00) .....

Concession (Newsletter by mail) (\$15.00) .....

E-mail Concession (Newsletter by email) (\$15.00) .....

Donation (\$2.00 and over are Tax Deductable) .....

I would like to purchase a copy of the Pool Exercise DVD (\$15.00) .....

TOTAL \$.....

Membership runs from July 1 to June 30 each year

#### RETURN COMPLETED FORM TO

Ankylosing Spondylitis Group of Queensland  
P.O. Box 193  
Taigum, Qld, 4018

Please make cheques payable to:  
Ankylosing Spondylitis Group of Queensland

The Ankylosing Spondylitis Group of Queensland complies with the Privacy Amendment (private sector) Act 2000 and will not sell your personal information to another organisation. You will be notified of Ankylosing Spondylitis Group of Queensland events and services. If you wish your name to be removed from our database at any time please write to us.