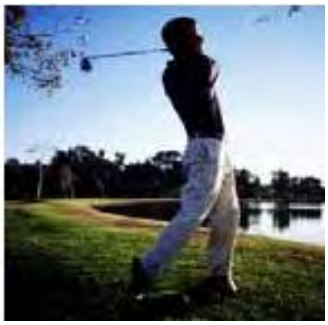
# ASTRETCH

**SUMMER 2020** **www.asaustralia.org**

**ANKYLOSING SPONDYLITIS AUSTRALIA**



## Disease Burden in AS and nr-AxSpA *summary by Margaret Lewington*

Axial spondyloarthritis (AxSpA), a chronic inflammatory form of arthritis that targets the spine, has long been broken into two types: radiographic — meaning that a patient has evidence of joint damage that can be seen on X-rays — and non-radiographic, which causes the same symptoms but a patient does not have visible proof of joint damage on X-rays. Radiographic axial spondyloarthritis is known as ankylosing spondylitis (AS).

While there is debate as to whether nr AxSpA and AS are 2 different diseases – since all people with AS go through a stage where X-rays of their joints didn't show definitive change – the prevailing theory is that nr-axSpA and AS are on the same disease spectrum.

Nr-AxSpA is not always a precursor that evolves into AS – different studies have found progression rates of nr-AxSpA to AS of 5% to 30% over as many as 30 years. There are some risk factors, such as strong family history, male gender, and high CRP.

Proof continues to mount that the disease burden of "both" conditions is the same.

Non-radiographic axial spondyloarthritis (nr-axSpA) is not a "less serious" form of AS. The burden of disease is similar in that the pain, fatigue, stiffness and the impact they have on a person's life is similar. Symptoms usually occur because there is inflammation in tendons or joints. That inflammation can lead to worsening of symptoms, but it may not lead to permanent changes. The burden of disease is dependent on the level of inflammation, not due to changes that can be seen on X-Ray.

One new study, published in the journal Annals of the Rheumatic Diseases, compared symptoms and disease activity among 185 people with radiographic axSpA and 484 with non-radiographic axSpA over a five-year period. They determined that there was no significant difference between the groups in terms of patient-reported symptoms, the number of sick days taken, and non-joint symptoms (such as skin, eye, or gastrointestinal problems).

"These highlighted results confirm the concept of axSpA as a single disease, which implies that both [radiographic] axSpA and [non-radiographic] axSpA patients should be treated with equal priority," the authors wrote.

First line treatment remains NSAIDS, exercise and lifestyle factors. For many, this reduces the level of inflammation and hence the symptoms. For those with persistent significant symptoms, biological medications may be considered.

In Australia, the TGA has approved both Etanercept (Enbrel) and Golimumab (Simponi) for the treatment of nr-AxSpA. As of December 2018, Simponi was listed on the PBS for nr -AxSpA.

Simponi is indicated for the treatment of adults with active nr-axSpA with objective signs of inflammation. PBS eligibility criteria includes meeting the ASAS definition for nr-axSpA, showing specific MRI evidence, elevated CRP, and one or more of Enthesitis(heel), Uveitis, Dactylitis, Psoriasis, IBD, or positive

*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.*

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## Disease Burden in AS and nr-AxSpA *continued from Page 1*

HLA B27. The person must also have failed to achieve an adequate response following treatment with at least 2 NSAIDS, while completing an appropriate exercise program, for a total period of 3 months.

More research is needed to determine if treatment with biologic medication prevents nr-AxSpA from progressing or causing radiographic change. Drug therapy isn't the only way to help keep nr-AxSpA in check. Weight control is an important factor. An appropriate, consistent, prescribed exercise routine (stretching, strengthening and fitness), is essential. A good balanced diet is important, as well as not smoking.

**Margaret Lewington**

*For further information please visit Creaky Joints: Burden & Progression.*

*Other references:*


*Towards better recognition and treatment of nrAxSpA' Rheumatology Republic, March 2019*

*'Clinical manifestations, disease activity and disease burden of radiographic versus non-radiographic axial spondyloarthritis over 5 years of follow-up in the DESIR cohort' C. Lopez-Medira, et al. Annals of Rheumatic Diseases, BMJ, Vol 79 2019*

*'Characteristics and burden of disease in patients with radiographic and non-radiographic axial Spondyloarthritis: a comparison by systematic literature review and meta-analysis' C. Lopez-Medina, et al Rheumatic and Musculoskeletal Diseases BMJ 2019*


## MRI thresholds for Axial SpA *summary by Margaret Lewington*

A recent German study which was published late 2019 in the Annals of Rheumatic Diseases, reported a very high incidence of false positives with MRI studies.

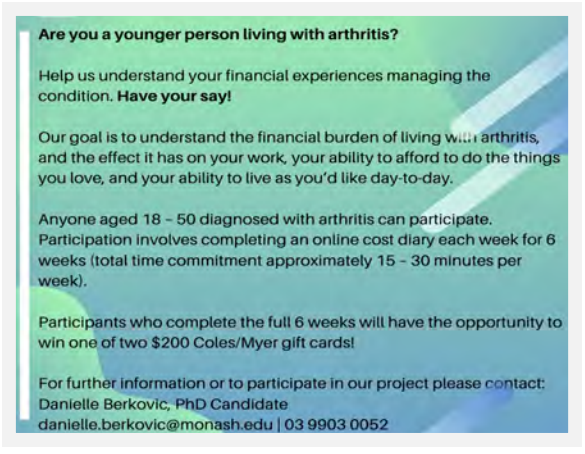
Approximately 800 healthy volunteers over the age of 45 underwent an MRI scan. The researches were just using standard ASAS AxSpA classification criteria to interpret the MRI findings.

The researches expected that around 1% of the people in the study would have undiagnosed AxSpA. However, when the results came back, they were much higher. Their study reveals that this traditional way of interpreting MRI has a high false positive rate.

The abnormalities they were looking at included structural sacroiliac joint bone marrow oedema seen in 17%, vertebral corners bone marrow oedema seen in 28% and post-inflammatory fatty lesions seen in 81% of the volunteers. These were not just seen once, but usually several times in many patients, which would usually lead rheumatologists to a diagnosis of AxSpA.

Hence, the researchers are now calling for caution around using a "positive MRI" as proof that a patient has axial SpA. The current definition needs to be updated. It is a large study and needs to be considered seriously. However, MRI should not be reviewed in isolation. It should always be interpreted in the light of clinical findings.

**Margaret Lewington**

## Article in Research Review (2019): Impact of sleep disturbance in Ankylosing Spondylitis summary *by Margaret Lewington*

Sleep deficiency adversely affects alertness, cognition, productivity, safety, learning, stress and mood and is implicated in physical and mental health outcomes. Spinal and nocturnal back pain are the greatest causes of fatigue in AS patients during the daytime. Several studies have shown that pain reduces the quality of sleep, which can ultimately increase the levels of fatigue. Therefore reducing pain could play a role in reducing fatigue in AS patients. Likewise, addressing sleep problems could improve pain, functional status and overall quality of life.

Sleep is a complicated state of consciousness and can be disturbed in many ways. A sleep disorder is any condition that interferes with sleep, excluding environmental factors such as sunlight, noise, excess heat or cold, movement and travel.

The main types of sleep disorders include: insomnias (trouble falling or staying asleep), hypersomnias (excessive sleepiness), parasomnia (unwanted experiences), sleep-related breathing disorders (trouble breathing), circadian rhythm sleep-wake disorders (sleep time out of alignment), and sleep movement disorders (movement during sleep).

Sleep patterns can also be disrupted by psychiatric and mood disorders as well as medical conditions. Life style factors that can disrupt sleep include poor sleep hygiene, effects of drugs or alcohol, and dietary changes.

Disrupted sleep, inadequate sleep duration, daytime fatigue, excessive sleepiness and irritability are highly prevalent in Australia, affecting between 33% and 45% of the population. Sleep disorders account for half of these problems with the remainder due to poor sleep habits or choices that limit sleep opportunity. The most common sleep conditions in Australia are obstructive sleep apnoea (OSA), significant insomnia and restless legs syndrome (RLS).

OSA is caused by collapse of the upper airway during sleep which triggers recurrent breathing disturbance. The prevalence of OSA in AS is higher than that of the general population with risk increasing with age and disease duration. As the disease progresses and the vertebral anatomy changes, the occiput-to-wall distance increases, which may result in increased neck thickness and airway hindrance. Several treatment options exist to treat OSA, including CPAP, oral appliances, etc.

Insomnia is characterised by frequent and persistent difficulty getting to sleep or staying asleep. Chronic insomnia is unlikely to spontaneously remit. It is best managed with non-drug strategies- CBT, etc, however if persistent, short term use of some medications may help.

RLS is a sleep related movement disorder affecting 5-10% of the population. It is characterised by the urge to move the legs because of uncomfortable sensations which are worse with rest or at night. Up to 50% of AS patients have RLS. Symptoms are only temporarily relieved by getting up and moving. The cause of RLS is unknown, but a dopaminergic dysfunction in the central nervous system is suspected. Hence, treatment is often dopaminergic medications or other CNS drugs (Lyrica, Neurontin), or opioids. CBT and good sleep hygiene may be of help, as well as compression devices, electric blankets, warm or cool baths, exercise, massage and stretching, and avoidance of caffeine, alcohol and tobacco.

*(My personal experience and long-time thoughts are that there is some influence from musculoskeletal tissues. As there is a higher incidence in AS patients with back pain, a physical and musculoskeletal reason seems even more likely than a 'chemical in the brain' and should at least be considered. Exercise, warmth, massage, stretching, physiotherapy treatment (exercise, posture advice and manual therapy), adequate NSAID use, could all be considered. Posture, especially sitting position is important. Sitting more upright and supported, avoiding lounge chairs. A wedge cushion, 2 inches at the back and slope to the front has been suggested for a long time and a 'backjoy' is a relatively new product that has similar effect and I have found personally and with many of my patients that this is extremely helpful.)*

**Sleep disorders are more prevalent in AS patients compared to the general population**, particularly in patients with high disease activity. A study of over 3000 participants found 70% of spondyloarthropathy patients could be classified as poor sleepers. Disturbed sleep is a major problems for AS patients; they often report poor quality sleep, multiple nocturnal awakenings, early morning awakening, sleep onset insomnia, difficulty awakening, and daytime malfunctioning leaving them feeling fatigued and impacting their quality of life.

A disruption in sleep with AS patients correlates with pain, stiffness and fatigue, which are indicators of high disease activity. Pain is the factor most strongly associated with fatigue and a decrease in pain improves both

## Impact of sleep disturbance in Ankylosing Spondylitis *continued from Page 4*

sleep and fatigue. Pain correlates with difficulty in getting to sleep and poor sleep quality, and stiffness correlates with waking difficulty and with feeling tired or clumsy in the morning. Up to 80% of AS patients need to move at night due to back pain, leading to waking up and interrupted sleep.

Fatigue has significant physical, social and psychological effects. Although it is not associated with absenteeism, it is associated with presenteeism and activity impairment. Despite the impacts of fatigue it is poorly managed in AS patients who often feel it is not properly addressed by their clinician and attempts to self-manage the symptom are usually unsuccessful.

**Sleep disturbance in many AS patients will be due to pain and disease activity**. It is important to speak to your health team (GP, Rheumatologist, Physiotherapist) if you are having difficulties. When disease activity fails to explain fatigue, alternative causes such as OSA, insomnia and RLS should be explored. Referral to a sleep specialist should occur when there are signs of OSA or when sleep hygiene measures have been unhelpful and disease activity is low.

Appropriate treatment to lower disease activity has been shown to decrease pain and hence improve sleep and improve fatigue. Exercise is an important component of the long term management of AS along with physiotherapy, and pharmacologic therapy – NSAIDs and Biologics.

**Sleep hygiene measures:**

Behaviour – Maintain regular sleep pattern even on weekends, develop a consistent relaxing pre-sleep routine, limit daytime naps to 30 mins, and get out of bed if unable to sleep after 15-20 mins.

Consumption – eat regular meals, avoid heavy/spicy foods close to bedtime, avoid nicotine products 2-3 hours before bed, limit alcohol use at night, avoid caffeine 8 hours before bed, review timings of any medications, ensure adequate pain or NSAID medication

Environment – Achieve adequate daytime light exposure, bath or shower up to 1 hour before bed, set alarm and turn clock face away, avoid using electronic devices in bed, keep bedroom dark, quiet, cool and comfortable

Activity – Complete moderate to vigorous physical activity for 30 mins at least 3 times per week and avoid vigorous physical activity close to bedtime (2 – 3 hours before).

**Margaret Lewington**

## Professor Rachelle Buchbinder AO

Our AS peer support groups in Victoria and Queensland in Australia, would like to extend our congratulations to Prof Rachelle Buchbinder on being awarded an AO, Officer in the General Division of the Order of Australia in the Australia Day honours 26 January 2020. She has been recognized for distinguished service to Medical Education in the fields of Epidemiology and Rheumatology and Professional Associations.

Currently, amongst her clinical and educational roles Prof Buchbinder is Director of the Monash Department of Clinical Epidemiology at the Cabrini Institute; NHMRC Senior principal research fellow at the Centre of Research Excellence for ANZMUSC; Co-ordinating Editor for the Cochrane Musculoskeletal Group; and key researcher with the Australian Rheumatology Association Database (ARAD). We have mentioned all of these groups, their research and publications in many prior editions of AStretch.

"Prof Buchbinder has been a strong supporter of involving healthcare consumers as research partners throughout the research cycle from planning, co-design and implementation." As mentioned by Musculoskeletal Australia on January 28, 2020. I think all our musculoskeletal consumer colleagues in the Australia and New Zealand Musculoskeletal Clinical Trials Network (ANZMUSC), Consumer Advisory Group, can attest to this commitment in all our activities by the ANZMUSC Chair, Prof Buchbinder. We look forward to working with Prof Buchbinder in future projects.

*Rachelle Buchbinder*

**Annie McPherson**

# Exercise Studies—fatigue and activity levels in AS *by S H Sveaas et al*

**High- Intensity cardiorespiratory and strength exercises reduced emotional distress and fatigue in patients with axial Spondyloarthritis: A randomised controlled pilot study.**

Scandinavian Journal of Rheumatology, 2018

S H Sveaas, et al

Objective: To investigate the effect of high intensity exercise on emotional distress, fatigue, and ability to do a full day's activities in patients with AxSpA.

Method: A total of 28 physically inactive AxSpa patients were randomised to either an exercise group or a control group. The exercise group performed 12 weeks of cardiorespiratory and strength exercises. The control group received treatment as usual.

Background: It has been reported that AxSpA patients have a higher risk of depressive and anxiety disorders and higher levels of emotional distress compared with the general population. Approximately 50% of patients experience severe fatigue. The reason for these complaints is not known, but several disease related factors, such as inflammation, deconditioning, medication, and sleep are thought to play an important role.

In the general population, it is well known that exercise has beneficial effects on emotional distress, fatigue and mood, but the impact of exercise on these parameters in patients with AxSpA have been little explored. Although emotional distress and fatigue are recognised as important symptoms, the latter being included as a factor in the BASDAI, these symptoms have seldom been explored as independent outcome measures in exercise trials.

Beneficial effects of flexibility exercises on emotional distress and fatigue have been shown, but there is a lack of randomised controlled trials that have investigated the effect of cardiorespiratory and strength exercises in this patient group.

Intervention: The intervention lasted for 3 months and followed the American College of Sports Medicine recommendations. Two days a week, the exercise sessions were supervised, and the participants performed high intensity interval exercise on a treadmill (4 mins of walk/ running at 90 – 95% of MAX HR followed by 3 mins of active resting at 70% of Max HR repeated 4 times). Thereafter the participants preformed 20 mins of strength exercises for major muscle groups (max 8 – 10 repetitions, 2 – 3 sets). Once a week, he participants performed a cardiorespiratory exercise session individually for 40 mins. The participants in the control group were asked to not change their physical activity habits.

Discussion: The results showed promising effects of high intensity exercises on emotional distress, fatigue, and ability to do a full days activities in patients with AxSpA. The results were large enough to be considered clinically meaningful and therefore indicating that exercise should serve as an effective treatment modality.

The positive effects of exercise on emotional distress and fatigue have been explained by both psychological and physiological hypotheses. The psychological hypotheses include distraction, increased self-efficacy, and social interaction. According to the physiological hypotheses, the increases in synaptic transmission of monoamines function in the same manner as anti-depressive drugs and the release of endorphins, which have an inhibitory effect on the central nervous system.

Another potential mechanism may be the anti-inflammatory effect of exercise, since inflammation is reported to be a predictor for fatigue in AxSpA. In the present RCT, we found reduced levels of pro-inflammatory cytokines in the exercise group, and this finding may be a possible explanation for the observed positive effects.

However, in contrast to anti-inflammatory medication, exercises may influence fatigue and emotional distress through several pathways. Thus, exercises may be especially important for patients suffering from complaints that are not caused by inflammation.

Conclusions: The results showed promising effects of cardiorespiratory and strength exercises on emotional distress, fatigue, and ability to do a full day's activities in patients with AxSpA. The findings need to be confirmed in a larger trial.

**Beneficial Long term effect on leisure time, physical activity level in individuals with AxSpA.**

Scandinavian Journal of Rheumatology, 2019

S H Sveaas, et al

Objective: To explore the long term effect of a 3 month exercise program on leisure time, physical activity levels in individuals with AxSpA.

Method: 100 individuals were included in a randomised controlled trial. The exercise group participated in a 3 month exercise program while the control group received no intervention. Physical activity during leisure time was measured with a questionnaire (physically active was 1 or more hours /week of moderate to vigorous intensity physical activity).

Results: At 12 months follow-up, significantly more individuals in the exercise group than in the control group were physically active, and exercised 2 -3 times per week.

Conclusion: A 3-month exercise program had a beneficial long term effect on leisure time physical activity in individuals with AxSpA, Thus indicating a more beneficial health profile. Still, few individuals continued the intensive program, and there was no difference between the groups in disease activity after 12 months.

# AS Exercises *by Margaret Lewington (Physiotherapist)*

**NECK POSTURE AND MOVEMENT** is important for all aspects of our daily activities. It is important to keep a good range of motion to be able to turn, look, back the car, and move about with ease. A stiff neck is often painful, and stretching the neck muscles often relieves tension, tightness and soreness in the muscles in and around the neck.

Daily stretching of the neck is a must for almost everyone with AS. The neck is almost always involved to some extent. Stretching can be done in the shower, sitting at traffic lights, at a computer rest break, or standing or lying. The following descriptions are in the sitting position, but as long as you maintain good posture, other positions are fine. Stretch in both directions. You may do each side alternately, or you may do all stretches first on one side and then on the other.

Stretch slowly, be relaxed, don't hold your breath, contract/relax and then perform a gentle but firm stretch. Listen to your body, don't force the stretch. If significantly uncomfortable on either side, leave out and try again another time. It may be due to inflammation or compression and may need to settle. If you experience any tingling, dizziness, or other strange feelings, stop and talk to your physio or doctor before trying again. You can do all the stretches at once or you may find it better to spread them over the day. Do the ones you find most helpful to you on several occasions throughout the day.

Sit well back in a chair with your low back fully supported and keep your hips, knees and ankles at 90 degrees and feet flat on the floor. Don't allow your pelvis to slide forwards.

## HOW TO STRETCH

To effectively stretch muscles, a long , slow sustained stretch is necessary, while keeping the body relaxed.

Some people like to just give a firm long stretch, or repeat several times with a short relaxation between.

Some find using the PNF—contract-relax-stretch method works best.

PNF is a method of stretching muscles to maximise their flexibility. A muscle will stretch further and more easily if it is first made to contract or work, then relax completely, followed by a firm and steady stretch. The sequence is "contract, relax, and then passively stretch". The objective is to have muscles contract isometrically ( without movement), then after relaxing, be passively stretched. Hold the stretch position, but keep yourself relaxed (don't hold your breath or tense your body).

First move in the direction chosen to the end of movement. Hold for 5-10 sec. Now make the opposite muscles work by very gently (20%)pushing back into your hand, for 3 sec, but don't let any movement occur. Often just moving your eyes to look is enough. Now relax for 1 sec with no movement and then try to go in the chosen direction a little further by passively stretching for 5 –10 sec. Repeat 3 times. When finished, push into your hand to slowly come back to the starting position.

## STRENGTHENING NECK MUSCLES

As well as keeping good range of motion, it is important to have strong muscles helping to keep you upright as well.

When sitting or standing upright, with good posture position, you can place your hand behind your head and push back into your hand as you resist the motion and make the muscles work isometrically. Relax and then repeat.

You can also do it as an active exercise. If you bend your head forward first, then actively resist as you push your head up to the straight position.

A towel may also be used. Loop the towel behind your head and hold the ends in front with both hands. Push your head back in to the towel, either holding still or with movement as you lift your head up.

In lying, you can push your head back in to the pillow or just onto the bed or floor surface or you can lift your head up a little first and then place you hand or a towel behind your head and push back to the flat position.

## POSTURE CHECK

Standing with your back to the wall, try to get your head to touch the wall. Don't lift your chin or drop it down. Keep your eyes level.

Keep your heels, hips and shoulders against the wall with straight knees. Let your shoulders relax, arms at the sides. Palms may face forwards. Pull your head straight back towards the wall, trying to touch or reduce the gap. Grow tall as if being pulled up to the ceiling. Gently relax any tension in your shoulders and body while trying to maintain the corrected posture. Hold the position for a little time, then relax briefly and try again a few times. Try to maintain this tall, straight posture as you walk away from the wall. This could be a daily exercise if it is a challenge for you or you may do it once a week as a postural check to ensure you are not slipping back.

## AS Exercises *continued from Page 6*

**Posture correction**

Grow tall, feeling the back of your neck lengthen. Pull your head back, tucking your chin in. Don't lift your chin up or drop it down. Keep your eyes level. Hold this position, but relax the muscle tension and breathe. You may push gently on the chin.

Note: return to this position before commencing each of the following neck exercises.

**Neck rotation/turning**

Sit tall, relax your shoulders, turn to look over your left shoulder. Place your left hand on your right/ front cheek. Keep your right arm either beside you, behind you, under your bottom or holding the chair. Use your left hand to help ease your head around further to the left until a stretch is felt. Push back into your hand a little to make the muscle work but not letting any movement occur, relax and then take the head around a little further. Repeat twice more. When finished, push into your hand to slowly come back to the front position.

**Neck side bending**

Sit tall, let your left ear drop sideways towards your left shoulder. Place your left hand over the top of your head (hold the side of your head or your ear to get a firm hold). Fix your right hand on the side of the chair to stop you lifting your shoulder. Take your head to the side until a stretch is felt in the right side of your neck. Hold. Push up into your hand a little to make the muscle work but not letting any movement occur, relax and then take the head over a little further. Repeat twice more. When finished, push into your hand to slowly come back to the upright position.

If you are familiar with this stretch and want a small variation which targets some of the neck muscles more specifically, you can change the angle of stretch just a little. Before you tilt to the side, look slightly to the right and then side-bend to the left, so that you end up looking slightly upwards and your ear goes just in front of your left shoulder, feeling the stretch slightly in the back of your neck. Also, look slightly to the left and then side-bend to the left, and your ear comes just behind your shoulder, feeling the stretch slightly in front. Only do this if you are familiar with your stretching routine.

**Neck flexion/forward bending**

A) Tuck your chin in, look down, curling the top part of your neck. Place your hand over your head, trying to curl and stretch the top of the neck at the base of the skull., don't just pull down on it. Push back into your hands, relax and stretch.

B) With the same position for your hand, this time relax the neck first and let your chin drop forwards, more towards your chest than tucking it in. Allow the whole of the back of the neck and the upper back between the shoulder blades feel the stretch. Still sit tall, don't slouch your posture.

**Neck extension/looking up**

It is very important to be sitting up tall. Tuck your chin in and then look up to the ceiling. Allow your whole head to move back, not just tipping from the top of your neck. Some find it helpful to put a hand behind the head to support and guide the head, especially if you are not very stiff. Place the other hand on your chin and ease the head back until a stretch is felt in the front of the neck. Push forwards, relax and then help it back. Do three stretches. It is very important with this stretch to push forwards to come to the upright position or use the hand behind your head to help lift, at the end and not to just let go and try to bring your head forwards unsupported.

**Neck diagonal/Levator Scapula stretch**

Turn your head to the left and a little forwards to look down towards your hip. Place your left arm up and over your head. Gently stretch forwards and down, feeling the stretch in the muscle that goes to your right shoulder blade. Push back into your hand gently, relax and stretch forward, down and across.

# Ankylosing Spondylitis Victoria Inc Report

It has been an extraordinary summer this year, many of our members and colleagues, have been impacted in by these horrific bushfires and drought. In the musculoskeletal (MSK) community many have commented on how these weather events have played havoc with their symptoms. We hope all our readers, friends and family members remain safe for the last of the summer months.

Generally the end of our, AS Victoria (AS Vic) year's is quiet, however this year we have fielded enquires from around both regional and metropolitan Victoria, ACT, Queensland and NT. We would like to welcome new member Greg Davis who has joined AS Victoria (AS Vic.).

We will be joining the Young Women's Arthritis Support Group members at their meetups/ social gatherings starting in Northcote, in the New Year on February 16. Both Dionne Lynch in Bendigo and Adam Collard in Korrumburra have been successful in organising regular events with local Peer Support Groups (PSG) to encourage others with AS or an MSK condition to join in with their discussions. We will be posting these dates and locations approximately one month in advance on our AS Vic Facebook and website pages.

"*Our work here is done*" almost….. at the University of Melbourne, Melbourne Medical School:

We have been informed this year, the Chronic Condition Patient Perspective program has been postponed to later in the year. Tamara Clements, Lecturer and Coordinator, Year 1 Doctor of Medicine has advised "The students will be attending clinical placements (in GP's) throughout the year. We remain committed to providing opportunities for students to hear from patient advocates, such as yourselves – it is so important that students understand the patient perspective".

We were encouraged to hear, this change is partly due to the informative presentations provided by our group of Chronic Condition patient representatives, including our MSK colleagues, and myself over the last 10 years. I would also like to acknowledge the work of our MSK colleagues Bill, Margaret, and Noel who all provided great encouragement and support for these talks over the years. The importance of the Patient Centered Care approach to healthcare and medical education has clearly informed this tertiary educational facility.

**Musculoskeletal Australia**

We had an interesting MSK Aust. patient Consumer Advisory Council meeting last November 2019, where high on the agenda was the progress of the "Stop the next Fracture" Fracture Liaison Nurse in public and private healthcare advocacy project, report by Osteoporosis Support Group of Melbourne's Beryl Logie.

Thank you to AS Victoria member, Rosemary Ainley for the links to the Creaky Joints' articles and for the information supplied by Barbara Brody (please see our summary on Page 1).

Thanks to all the team at AS Victoria, who are looking forward to a busy year supporting those in the AS community and continuing with our AS community work.

*Annie McPherson*

**Annie McPherson-President.**

**Young Women's Arthritis Support Group – Bendigo, Victoria.**

The Bendigo YWASG has been running for nearly 18 months with a small supportive group meeting monthly for a coffee and chat. The host Dee has Ankylosing Spondylitis while the members have a variety of arthritis conditions and fibromyalgia and range in ages 30 – 50 years old. Some months women attend the group by themselves, however other months they may bring their children or parents along for support.

*Dionne Lynch*

The women find the regular catch ups supportive due to there being very limited regional medical support available so it's beneficial to have that emotional support in between appointments.

Newcomers are always welcome and there is no obligation to attend each month. The group leader Dee is more than happy to chat or meet up with anyone prior to attending the group catch up – please get in touch via the YWASG Facebook page or website.

**Dionne Lynch– North Central Region Representative**

**South Gippsland Arthritis Support Group (SGASG).**

The South Gippsland MSK Peer Support Groups Coffee and Chat sessions have resumed for the year in Leongatha at the RSL on the first Monday evening of the month and Korrumburra on the first Tuesday lunchtime. All new members and visitors are well.

Please support our bushies and visit Gippsland again, preferably with an empty eski and car boot!!!

**Adam Collard**

*Adam Collard*

## AS Group of Queensland Report *by Graham Collins*

Well here we are, another year.

As 2020 gets underway, the numbers at the Tuesday night hydro sessions at Royal Brisbane and Women's Hospital are pleasing.

Our resident physiotherapist, Margaret Lewington, is whipping us into shape with all the usual stretches and exercises and a few new ones to keep us on our toes.

We have had a few new starters in the pool this year with Paul and Katrina to name just two. The older I get the more I appreciate the hydro sessions as I know it is something I can continue to do as I age. If you haven't tried hydrotherapy or been for a while, you don't know what you are missing.

We ended the year with a Christmas get-together at Rod and Margaret Lewington's home. We enjoyed good food, good company, the odd glass of wine and a dip in the pool. Many thanks to Rod and Margaret for hosting the Group's Christmas celebration.

*Hydrotherapy at the Royal Brisbane Women's Hospital*

We had another great pizza night on Tuesday, Feb 18. These are always a great time to have a chat, catch up and support each other. We have them several times each year and anyone is welcome, whether you come to hydro or not. Please look out for the next date.

Remember, keep moving, as sitting is the new smoking.

**Graham Collins**

## Hydrotherapy Classes

**BRISBANE (QLD)**

Sessions supervised by **Margaret Lewington (**Physiotherapist).

**When:** Tuesday evenings.

**Time:** 6:30 - 7:30pm

**Where:** Hydrotherapy Pool

Lvl 2, Ned Hanlon Building

Royal Brisbane & Women's Hospital

Butterfield St, HERSTON.

**Cost:** $15 or 10 classes for $140

**Enquiries:** Margaret on

0404 414 501 or 07 3376 6889

**PERTH (WA)**

Sessions supervised by experienced Physiotherapists.

**When:** Monday evenings (Public holidays excepted).

**Time:** Two sessions.

Hydrotherapy pool 5:45 or 6:45pm.

Gymnasium & pool 5:45 & 6:45pm. For those current group members and those who have recently participated in an AS program with the Hospital or the Arthritis Foundation.

**Where:** Arthritis Wyllie Centre,

17 Lemnos St, SHENTON PARK.

**Cost:** $12

**Enquiries:** (08) 9388 2199

www.arthritiswa

### Facebook Groups

AS Brisbane

AS Sunshine Coast

AS Group VIC

## Calendar of Events

**VICTORIA:** Refer to www.asvictoria.org for details or Annie McPherson mob: 0408 343 104

**March 2020:**
Monday 02nd :Coffee & Chat 6:00 – 8:00 pm : Leongatha RSL, Leongatha. Contact Adam Collard Mob. 0408 353 785
Tuesday 03rd :Coffee & Chat 2:00 – 4:00 pm : Korrumburra Recreation Centre, Korrumburra. Contact Adam Collard Mob. 0408 353 785
Tuesday 17th :Spondylitis Awareness Stand 12:00 – 4:00 pm : Austin Health, Tobruk Centre, Heidelberg. Contact Annie McPherson Mob. 0408 343 104
Saturday 28th :"Farmworld", Lardner Park at Warragul. Contact Adam Collard Mob. 0408 353 785
Sunday 29th :YWASG meetup 10:00 am -12:00 : Coffee Club Café, Corner Edward & Queen Sts, Bendigo. Contact Dee Lynch Mob. 0417 556 080

**April 2020:**
Mon. 06 Coffee & Chat, Leongatha -details as per above
Mon. 07 Coffee & Chat, Korrumburra -details as per above
Sun. 26 YWASG meetup, Bendigo - details as per above

**May 2020:**
Sat. 02 World AS Day social event :12.30 pm Lunch at Berwick Inn , Berwick. Contact Annie McPherson
Mon. 04 Coffee & Chat, Leongatha -details as per above
Mon. 05 Coffee & Chat, Korrumburra -details as per above
Sun. 24 YWASG meetup, Bendigo -details as per above
Tues. 26 Austin Health Spondylitis Awareness Stand, 12:00 - 3:00pm, Heidelberg, Contact Annie McPherson

*Caulfield Community Health Service: AS exercise program : Dates to be advised. Please contact Annie McPherson for details.*

**QUEENSLAND:** Refer to www.asaustralia.org/qld/ for details or Mark Robinson mob: 0407 425 750

Saturday May 2nd on **World AS Day**: Picnic in the park with exercises. Details TBA.

## Picnic in the Park Family Day

**To celebrate World AS Day on Saturday, 2nd May.**

**Support for people with AS and for their families.**

**Come along, to meet and chat with others.**

**Share a meal or drop in for a short time.**

**We'd love to see new faces.**

**All welcome!**


**We plan to find a park with exercise equipment for those who might like to do a little exercise or go for a walk together.**

**Details to be announced.**

## Global AS Summit 2020

**This year ASIF, the international patient society, are again supporting the SAA's Global Summit.**

**There will be a week of videos all about Ankylosing Spondylitis which our members will be able to register for and watch for free.**

**This will be at sometime around World AS Day (2 May, 2020). Further details to be announced.**

## General Information

**Ankylosing Spondylitis Groups of Australia**
www.asaustralia.org

**Ankylosing Spondylitis Victoria Inc**
www.asvictoria.org

**Arthritis Australia**
www.arthritisaustralia.com.au

**Musculoskeletal Australia** *Please check this site for educational health consumer webinars throughout the year.*
www.MusculoskeletalAustralia

**Spondylitis Association of America (SAA)** *Contains message boards, online chat forums, and a members only section for resources*
www.spondylitis.org

**Ankylosing Spondylitis International Federation (ASIF)**
www.asif.info

**The National Ankylosing Spondylitis Society (NASS - United Kingdom)** *Contains an excellent questions and answers section and downloadable guidebook - A Positive Response to Ankylosing Spondylitis-Answer and practical advice.*
www.nass.co.uk

# Ankylosing Spondylitis Victoria Inc
# Membership Form

*AS Victoria Inc is a Move muscle bone & joint health Peer Support Group*

**Who we are and what we do....**

AS Victoria is an organisation of people with Ankylosing Spondylitis who wish to improve knowledge and ability to manage the condition. Our group shares a number of goals and objectives for people and families living with Ankylosing Spondylitis.

**We aim to provide the following**:

- Provide a forum for the exchange of ideas and experiences.
- Distribute information to patients and medical professionals on AS.
- Provide and co-ordinate educational information, events, workshops and seminars on AS.
- Co-operate and interact with local, interstate, international Arthritis and peer support groups including participation in their events and activities.
- Arrange social events and activities for our group members, their families and friends

**Some of the benefits of belonging to our group:**

- AStretch newsletter
- Seminar evenings with excellent guest speakers
- Improved awareness of AS and the AS community
- Opportunities for interaction with other members at social gatherings and activities
- Land exercise DVD for people with AS

**Membership Details**

**First Name:** _____ **Surname:** _____

**Mobile:** _____ **Home:** _____

**Email:** _____

**Address:**

_____

I wish to become a member of AS Victoria Inc support the purposes of the organisation and agree to comply with the rules for an incorporated association under section 46 of the Associations Incorporation Reform Act 2012.

**Signed:** _____ **Date:** _____/ _____/ _____

**Send to:**
**AS Victoria Inc**
**PO Box 3166**
**Burnley North 3121** **asvicweb@gmail.com** **www.asvictoria.org**

**Ankylosing Spondylitis Victoria Inc complies with the Privacy Amendment (Private Sector) Act 2000 and will not sell your personal information to another organisation. You may be notified of AS Victoria Inc events, services and ways of assisting us to maintain these services. If you wish your name to be removed from our data base at any time please write to us. AS Victoria Inc passes on to members a variety of information on health and medical issues only for general, educational and informative purposes. AS Victoria Inc is not diagnostic or prescriptive and does not replace the services or advice of a qualified health care professional or purport to do so.**

**Membership Type**

☐ **New** ☐ **Renewal (annual 30th June)**

☐ **Mail out# membership ($25.00)**

☐ **Concession* Mail out# membership ($20.00)**

☐ **Email member ship ($20.00)**

☐ **Concession* email membership ($15.00)**

Donation: $ _____ **(Donations over $2 are tax deductible)**

**Total:** $ _____

Cheque, money order or direct deposit -

AS Victoria Inc NAB BSB : 083 399 Account : 154321878

**#**Mail out membership all correspondence will be sent by Australia Post
******Concession rate available for pensioners, unemployed with health benefit card and full time students with student card.

***Statistical Information*** *(Optional):-*

**1.** Are you a member of Arthritis Victoria? Y / N

**2.** Can we pass on your contact details to other members of the group in your area? **Y / N**

**3.** Gender **M / F**

**4.** Year of Birth: _____ **5.** Preferred Language: _____

**6.** Do you suffer from A S **Y / N** **7.** Do you know someone who suffers from A S **Y / N**

**Do you have any other conditions?**

……..…….

**Are there any specific activities you would like us to organise?**

……..……..

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