

WINTER 2011
NEWSLETTER

AStretch

ANKYLOSING SPONDYLITIS AUSTRALIA

www.asaustralia.org



Raising Awareness of AS to Physiotherapists - by Margaret Lewington



Physiotherapist Margaret Lewington

A further module, which will be a practical day, to support and expand on these, is currently being developed by the physio advisory group. This will aim to increase practical skills of assessment and treatment.

There have been seminars for physio's held in several states. Titled – 'AS you see it' – they had a large AS focus but also included other inflammatory arthritis topics.



Ross speaking at the Brisbane event

The last year has seen several activities which have had the aim of increasing awareness of AS to the physiotherapy population. I have reported on a few things in previous newsletters, especially the formation of an advisory group of physio's representing each state and an article that was published last October in our National Physiotherapy newsletter – InMotion.

Since then, there have been several other activities. An online education program with 2 modules has been developed. This is to help physio's build their knowledge and skills and gain confidence in assisting patients with AS to manage their condition effectively. The learning modules are case based and cover differential diagnosis, assessment and disease management of AS. They have been endorsed by the Australian Physiotherapy Association.



Sharon speaking at the Brisbane event.

Talks covered the disease, radiology, medical therapies and physiotherapy management. At each event, one or two patients with AS (Ross and Sharon up and left side pictured spoke at the Brisbane event) were invited to tell their story to the audience. This was well received.

They were all very well attended with close to 1,000 physio's attending one of these events. The first pres-

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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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Raising Awareness of AS to Physiotherapists - continued from page 1

entation was in Sydney, followed by one in Melbourne and Adelaide on the same day – with some of the presentations being video linked from Melbourne to the Adelaide audience. This was the same for Brisbane and Hobart. The Brisbane one was also available as a webinar event both for physio's anywhere in Australia as well as some international physio's linking in. Abbott pharmaceuticals are to be thanked for supporting these events.

The exercises that were done with Michael Slater, that we have reported on previously, have now been put on a DVD.

This DVD was sent to all physio's who are a member of the APA – Australian Physiotherapy Association. It was stuck on the front cover of the newsletter – InMotion – with an article about Michael, and an interview with both Tony and Margaret – the 2 physios who helped in the production of it. There has been some delay in getting these uploaded to the Arthritis Australia site – but keep checking – they should be there soon. If you are seeing a physio – check with them if they have looked at their DVD.

The Physiotherapy Association also has a more clinical newsletter, InTouch, which goes to all physio's with an interest in musculoskeletal conditions. Margaret was invited to write an article for this. It became the feature article, with the cover devoted to it as well as the article inside 'Physiotherapy – an essential partner in the treatment and management of AS'.

RHPA Annual Meeting Report by Margaret Lewington

Report of Annual National Scientific Meeting of Australian Rheumatology Association and the Rheumatology Health Professionals Association - 2011

The meeting was held in Brisbane in May, with a very good attendance of rheumatologists, physio's, nurses, scientists and other health professionals interested in Rheumatology.

A very high standard program, as always, was presented with a good representation of Ankylosing Spondylitis and Spondyloarthropathy topics.

The team from PAH were well represented with Linda as an invited speaker for the RHPA on the topic of 'A disease specific service – the AS experience', and Janelle – 'Offering your patients more – at home and abroad'.

Linda and Janelle both had free papers and posters accepted as well. We will report on some of these topics in future issues. Louise Bassingthwaite spoke on the issues of driving and medical fitness. She has kindly written an article for this issue of our newsletter on this topic.

A full session in the ARA program was devoted to Spondyloarthropathy with presentations on Psoriatic Arthritis and Ankylosing Spondylitis and several talks and posters on current research, science and genetics topics. It is great to see the interest – both of the presenters and in the audience.

Driving with AS

by Louise Bassingthwaight
Occupational Therapist Princess Alexandra Hospital.

Driving a car is an activity that enables engagement in daily life tasks. Driving and the use of a car allow people to maintain an active and meaningful lifestyle because they are easy and convenient and allow access to those activities that require leaving the house. Driving a car is often time efficient, allows for spontaneity and gives control to the person.

Driving often enables people to maintain valued roles in life. These can include continuing in paid employment, volunteering, pursuing a hobby, being a grandparent and helping others in our local community. Maintaining involvement in roles of ones own choosing, are vital in shaping and supporting our sense of who we are.

Whilst many factors contribute to safety on the road, driver health is an important consideration and drivers must meet certain medical standards to ensure that their health status does not increase the risk of a crash in which they or other road users may be killed or injured.

How this legislation is enacted is different across the country, with processes varying considerably between all of our states and territories. However, the following roles and responsibilities are consistent across Australia.

Jet's Law

In 2004, a driver with epilepsy had a seizure whilst driving and crashed into the car in which Jet Rowland was a passenger. The accident killed Jet, severely injured his mother and eventuated in paraplegia for his brother. Medical condition reporting legislation was introduced following this event, to minimise the possibility of similar tragedies occurring again.

However, driving is a complex task



requiring effective interaction of vision, movement and thinking skills. A change in any of these areas can impact upon driving safety.

According to this law, it is the drivers responsibility:

- To report to the Driver Licensing Authority (eg. Queensland Transport, VicRoads, RTA) any condition likely to affect ability to drive safely
- To respond truthfully to health professionals regarding health status and the likely impact on their driving ability
- To adhere to treatment
- To comply with requirements of conditional licence including periodic medical reviews

So how does this apply to individuals who have Ankylosing Spondylitis?

Amongst other symptoms, AS can cause pain, fatigue, reduced joint range of movement, reduced muscular strength and decreased reaction time. In thinking about how AS may impact upon vision, movement and thinking when driving:

Vision may be affected by an inability to move enough resulting in:

- Reduced awareness of other

road users such as cars, pedestrians and bike riders, and

- Reduced awareness of various road signs and road markings

Reduced range of movement, strength and reaction times may result in:

- Difficulty moving between the accelerator and brake
- Challenges holding and turning the steering wheel
- Problems in doing safe practices such as making blind spot checks before changing lanes and
- Difficulties reacting to sudden changes on road

Pain, fatigue and the impact of medications may impact upon thinking resulting in:

- Difficulties staying alert
- Difficulties being focused and being distracted from important driving tasks
- Impaired judgement
- Reduced capacity to multi-task

What Does Jet's Law mean to me?

Under Queensland law, you **must** report any long term or permanent medical conditions that impact on your ability to drive, to **Queensland Transport** .

Queensland Transport requires you to obtain medical clearance to be able to resume and/or continue driving. This clearance needs to come from your doctor.

If your doctor is uncertain about how your driving may be affected or when it is thought that vehicle modification or other strategies may be of benefit, an Occupational Therapy Driving Assessment may be helpful.

Occupational Therapy Driving Assessments are conducted by occupational therapists who have additional training in the area of driving assessment and rehabilitation. The assessment is customised to obtain information relevant to the driving potential of an individual and subsequent crash risk. The assessment of a driver is not purely to identify safe and unsafe drivers but must also determine whether the driver would benefit from driving rehabilitation, vehicle modifications, driving restrictions or other interventions.

So what does an occupational therapy driving assessment entail? Firstly an **off road assessment** is undertaken. To the disappointment of many, this is not a 4WD off road expedition, but rather a battery of evidence-based evaluations conducted within the department. Vision, physical skills (eg. movement and coordination) and thinking ability (eg. being able to attend to a couple of tasks simultaneously) are reviewed. The purpose of this element is:

- to ensure essential criteria for driving are met.
- to identify any factors which require closer examination on road.
- determine the need for vehicle modifications.

The **on road assessment** is conducted along a route including a variety of driving and road situations deemed to be essential for competent driving. The individual drives the car with required modifications in place (whenever possible). The driving instructor sits in the front passenger seat having access to dual controls to enable safe passage of the vehicle and the occupational therapist sits in

the rear passenger seat, observing and recording driving behaviours and practices.

Following the assessment, three outcomes are possible.

- Firstly, no impact of a persons medical condition may have been identified and it is recommended that they be considered medically fit to drive.
- Secondly, a remediation or rehabilitation program may be devised. This program may aim to develop operational control of the vehicle, as is the case when people require modification to the car. The program may also be required to address tactical and strategic elements of driving such as observational skills, lane positioning, planning and judgement and hazard perception. In such situations a program is devised, progress is monitored and a final recommendation is proposed at the conclusion of the program.
- Finally, it may have been observed that the medical condition does in fact impact upon driving performance and that remediation of identified areas of concern are not indicated. In which case, it is recommended that the individual is NOT medically fit to drive.

What Can I do to Keep Safe on The Road?

Firstly, think about driving and transportation issues early. Just as we spend many years planning for our retirement from work, we also need to consider how we shall continue being active in our community when we need to cease driving.

Enhancing physical skills:

- Keep as physically fit as possible (engaging in regular activity)
- Consider purchasing a different car eg. An automatic rather than

manual or a smaller vehicle with power steering

- Adapting vehicles. This may initially be minor changes such as the modification of the key to allow easier engagement of the ignition. As the condition progresses more involved changes may need to be evaluated by a driver trained Occupational Therapist.



Blind spot mirror



Panoramic rear view mirror



Seat Back Support

- Have regular eye check ups with regular review of prescriptions.
 - Consider altering driving habits e.g. Avoid driving at dusk when observation can be very challenging.
 - Keep the windscreen of the vehicle clean.
- energy conservation and joint protection strategies.
- In summary, driving is very often an important activity which is highly valued. Whilst the importance of maintaining connection with our community is valuable, this needs to be weighed up with the potential public safety risk associated with driving. Help and support is available to assist you consider your driving needs.

Enhancing thinking and reasoning skills:

- Have your doctor review your medications regularly
- Avoid driving when fatigued or tired
- Change driving route by planning and pacing the activity, especially on longer drives
- Minimise distractions (eg turn mobile phone off, turn off radio, selective passengers in the vehicle)
- Drive at times when comfortable: eg. Not peak hour, not when raining, not in new places.
- Use other transport options eg. Buses, taxi, car pooling. Having a broad range of transport options can ease the process of retiring from driving
- Keep up to date with road rules
- Talk to your doctor and other health professionals about driving. They may have hand-outs about arthritis-friendly vehicle features (eg. Swivel seats, back supports), or tips for driving which may include

More Information?

To locate a Driver trained Occupational Therapist, contact OT AUSTRALIA at www.ausot.com.au and follow the links to various states or territories to find an OT near you.

To contact your Driver Licensing Authority, follow the following link to locate your state or territory branch www.austroads.com.au/aftd/drinc.html

The Times They Are a-Changin by Greg



unbearable at times. In the middle of the night my wife would place a doubled towel over the length of my back and iron me with a warm dry iron to give me pain relief. She was very careful not to burn me, one very good reason why this is not a recommended technique! When I was stiff and sore, I would drag myself into a very hot shower. Eventually pain killers and anti-inflammatory suppositories were the medications I used to manage my AS. My whole focus had become to “do what it takes” to stay at work. Then early one beautiful winter morning in 1990 during the half hour drive to work, I literally watched two knuckles on my right hand slowly swell, become red, inflamed and sore to touch. I remember this event clearly as it marked a major turning point in my life. Within the year most of my other peripheral joints were affected. It seemed that as I favored one sore joint, the other joint that was taking the extra load became the new focus of attack.

to see if I could do anything to improve my AS. It seemed like a reasonable thing to try given my circumstance. His testing did seem to show that there were certain triggers that aggravated my AS. I'll not mention them here because, from what I understand, my triggers are not necessarily other people's triggers. The real break through for my wife and me however, was that his testing showed us my disease 'process.' If I did come into contact with something that severely aggravated my AS, I would become extremely angry, mostly irrational then leading into severe joint pain and depression.

My wife became very adept at recognising these signals. She would say to me, *"Greg, you are having a flare up; It might be good to go and lie down."*

This was how we coped. I would sleep through the initial angry

Some of Bob Dylan's work seemed to strike a chord with me as I was growing up and still strikes a chord with me now. I wasn't really into the social change aspect; I just enjoy the sound of some of his songs. When asked about the title of his second album Dylan said, "I didn't mean 'The Times They Are a-Changin' as a statement ... It's a feeling." When reflecting on my AS and the impact it has had on my life, I too get the feeling that the times, they are a-changin'.

My AS was first diagnosed in 1984 by my local GP, Dr Phil. It seems diagnosis by a GP was a little unusual at the time but Phil had another patient with AS so he recognised the symptoms immediately. I was 24 years old, just married and I thought I was bullet proof. My wife was a teacher working at the local high school and I had a very physically active job working as a mine surveyor. Even though I had my share of aches and pains, life was pretty good. My doctors' prognosis, though a cause for some concern, wasn't something I placed any emphasis on because "It wasn't going to happen to me." Little did I know that my life was about to change dramatically.

Over the next few years the disease slowly and progressively calcified my spine and neck even though I had a physically active job. The pain was

My wrists, elbows, shoulders, hips, knees, ankles and toes were all inflamed and very sore at some point in time. Not only was it a horrible time physically, it was also very trying mentally, emotionally and spiritually. My AS and how it had affected me, was now the reason I had to leave my job. I could no longer work and support my young family. For me providing for my family was a very important role. My capacity to do that was now almost gone. It was a huge sense of loss.

Some of the stages of the Grieving Cycle come to mind. Initially there was a sense of denial, "This won't happen to me, I'll get back to work." There was also anger at why this was happening to me. I was depressed at times, just too down to do anything. I'm not sure how my wife coped because she too was walking down this path as she tried to help me.

Then in 1992 I heard about a clinic in Melbourne run by a Doctor, who was considered a bit of a medical maverick at the time. He was researching what effect food/environment had on certain medical conditions. I went to his clinic



stage of a major flare up. Believe me, after a good rest, a nice long hot shower and a bit of a stretch I was able to face the world again even though I was still pretty sore in the joints.

My wife also realised that the happy go lucky guy she married

was still there, he was just having a flare up at that point in time.

Another major change in our lives occurred when we attended the AS Symposium in Brisbane in October 1998.

Previous to this I had not really come into contact with anybody else who was suffering from AS. I noted in the 2010 Winter Newsletter that Sharon also commented about this in her article.

The Symposium introduced us to many amazing people who along with their carers were trying to learn more about their disease and also to some sufferers who were coping with AS on their own. It also introduced us to our physio Margaret Lewington, the AS Group of Qld and AStretch. Being able to share this walk with others is extremely important and for me these contacts have been an important and invaluable way to do that.

An advertisement placed in AStretch alerted me to the AS Clinic at the PA Hospital. A visit to the clinic introduced me to Dr Matthew Brown, a rheumatologist. I can remember Matthew commenting at the time that I was one of the worse cases of AS that he had seen. It's nice to be "special"! After a small stint at the PA in November 2006 and a plethora of testing and x-rays, Matthew formulated a course of action.

This included the use of a TNF blocker (if I qualified) and a few operations starting with total hip replacements. Wow!!! The TNF blocker, well yeah, maybe. Total hip replacements, hmmm, I'd have to think about that one. I qualified to start on the medication and it's now been a few years down the track. Blood tests such as ESR and CRP, which were always extremely high, are now back to normal. Pain levels are manageable without me taking any other medication such as anti-inflammatories.

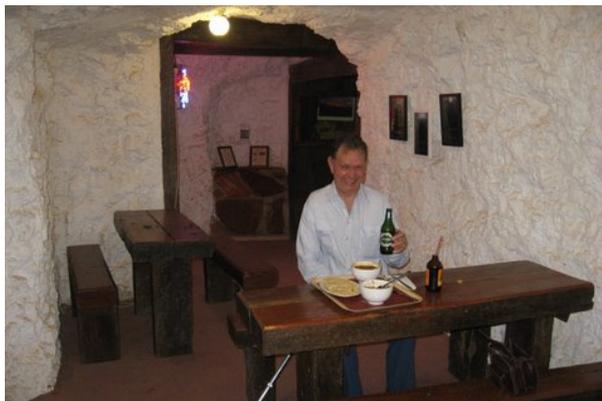
My flare ups are minimal and my emotions are more stable. I did get several bouts of iritis but Matthew has changed me to a different TNF blocker to help with that. I also have the privilege of participating in the

trials and ongoing research work that Matthew is conducting which is providing valuable insights into this insidious disease. The TNF blockers have changed my life. If only we had this medication back in 1984.

It's now my prayer that current sufferers who aren't yet eligible to take these medications will have access to them very soon so that they can also be life changing for them. I'm also hoping Matthew's research will be life changing for future AS sufferers. The times they are a-changin.

And the hips? Well, yes I did have the hips replaced in March 2008. As my movement was severely restricted by the fusion in both hips the orthopaedic surgeon decided to replace both at the same time. Two fully functional and moving hips ensured more effective rehabilitation.

This operation has also been life changing. I am now able to stand straighter and walk without the aid of my walking stick around the home. Odd jobs around the house are now possible (AS permitting) including the vacuuming and washing up. Remember guys, I thought I had lost what I considered to be my most important role, the ability to provide. Well, I have discovered that I am able to help out in other ways. My wife certainly appreciates my helping out. Thinking outside the box has

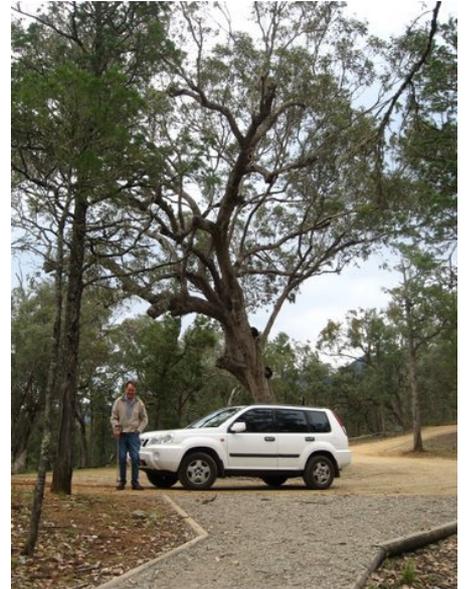


also led to another important change in my life.

Total hip replacements have meant that I am now back driving a manual car.

I have regained my license. With flexible hips it's now possible to op-

erate the clutch, brake and accelerator. Unfortunately my spine and neck are totally fixed so I couldn't drive a car across an intersection



safely. But, we have technology! A camera system was designed by Jos Hahn of Syncro Multi Eyes and adapted specifically for my situation. Infrared cameras (so I can also see at night) were fitted to the wing mirrors and rear of the car. These provide good visibility up and down the road. Two small angle cameras fitted on either side of the car check intersections. Two wider angle cameras check intersections that are more acute as well as the left and right blind spot. A 5th camera checks the rear for reverse parking.

Each camera is individually selected by flicking switches attached to the gear stick and the video signal is relayed from the camera to a DVD screen attached to the dash. I can now select any camera very quickly. Louise Bassingthwaite, an Occupational Therapist from the Driving Assessment and Rehabilitation Service attached to the Princess Alexandra hospital helped with Transport Department approval.

The whole process did take some time and included the assessments and several driving lessons with a driving instructor experienced at teaching people with disabilities. It was very important to slowly work through all the steps of this process

as driving safety is paramount. The assessments were conducted in traffic in Brisbane so my driving strengths and weaknesses were easily identified.

My inability to check for oncoming traffic at intersections or car blind spots precluded me from driving. Having the wing cameras fitted to the car was a means to overcome this.

Another aid I use is a flexible swivel cushion that I sit on, which improves my turning range. The driving lessons with a driving instructor were important so that I could familiarise myself with, and refine, the camera selection process.

A safe driving experience for all concerned is the key and it took some time to get it right. I had to get used to the switch controls, judging distances with the cameras and taking more time to scan for fast oncoming traffic, especially at intersections. My instructor stressed the importance of taking the time needed to make safe decisions.

After my license was approved (conditional upon my using cameras and a swivel seat), my wife and I decided to embark on an 8200km driving holiday to Broken Hill, Adelaide, Melbourne and Canberra to visit family and friends, something we never thought would be possible. I was able to safely drive all the way and appreciated the benefits of our GPS when driving on unfamiliar roads, especially in the built up areas. The GPS allowed me to concentrate on my driving

rather than having to focus on navigation. We had a wonderful time even though I now had two women (my wife and the GPS) telling me where to go! As my wife is an avid photographer there were plenty of stops along

the way which provided valuable opportunities to rest and stretch.

The Twelve Apostles, the Great Ocean Road and experiencing snow for the first time at Charlottes Pass were real highlights. So after 30 years suffering with AS what does the future hold? Well, there is some talk of an aortic valve replacement. There is also some talk of total knee replacements.



My wife said to me as we approached my 50th birthday, "Greg, you are feeling a lot better now at 50 than you were at 40, and we'll cross those bridges when we come to them." What about all that money I spent on alternative/complementary therapies? My wife's view is that al-



ternatives may not have really helped to control the progression of my AS but perhaps I'm able to deal with it's consequences a lot better because of them. Acupuncture and meditation have certainly helped me

at times. Some supplements have also helped to improve my energy levels. Phil (my GP) had this to say about the subject, "Greg, if I were in your situation, I would have done the same. Medical science didn't have a lot to offer you back in 1984." Medical science now **HAS** something to offer. What would I have changed? Sharon (Astretch Winter 2010), Steve (Astretch Spring 2010) and Erin (Astretch Summer 2011) all

talk about the difference hydro is making in their lives. Remember that I had a physically varied and active job.

What I didn't do however was **FIGHT** to maintain the end range movement in my joints which I progressively lost. It's now my belief that hydro would have played a major role in helping me to control the progression of what has been for me a slow and relentless disease.

What has helped? Interestingly, it's been a trilogy of H's, Humira (TNF blocker), Hips and Hydro.

So in closing perhaps we can leave the final thoughts to Bob Dylan:-

*If your time to you
Is worth savin'*

*Then you better
start swimmin'*

*Or you'll sink like
a stone*

*For the times,
they are a-
changin.*

AS Exercises

by Margaret Lewington
Physiotherapist

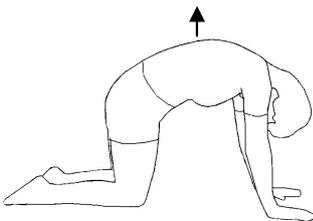
In this issue we will do some exercises in the 4 point kneeling position. Ensure your hands are below your shoulders and your knees below your hips, for a stable and comfortable position. If you have soreness in your knees, you may like to use a small cushion or a folded towel under your knees. Having an exercise mat with high density foam is also a good investment.

1. ROCKING

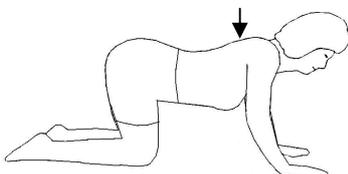
In the four point kneeling position, gently rock forwards and back. This can give relief when you have back pain. It may be a small movement or you can make it bigger. Keep it smooth and rhythmical. Gently pull your belly in, to activate your deep tummy muscles and give support.

2. CAT STRETCH

Arch your back upwards – especially the low back. Tilt your pelvis, tucking your tail bone under. Look down.



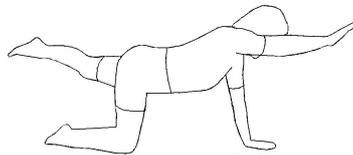
Now reverse this position and sag – dropping your tummy to the floor. This time your low back will move more easily and you need to emphasize your upper back – (between your shoulder blades) - breastbone to the floor. Look forwards, but not up too much (as this will shorten the back of the neck).



3. ARM and LEG LIFT

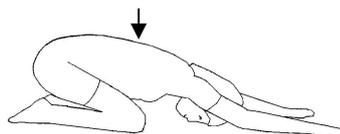
Keeping in the mid position, turn your tummy muscles on to keep your body steady and balanced. Straighten one arm out in front and the opposite leg behind. Hold this position for good stability and also for strength of the back and buttock muscles. Stretch long through your body, from finger tip to toe. Change to the other limbs. You may also like to try with the same arm and leg.

If you are not steady—start by doing with just an arm or just a leg on their own.



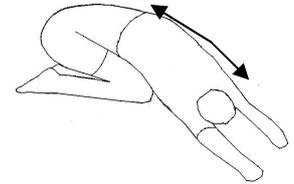
4. BACK STRETCH

Keeping your hands in the same place – sit back on your haunches – bottom to your heels. Try to drop your chest as low as possible to the floor and look down at the floor. You may like to just lean back into this position and have a good long slow stretch or you may rock back several times, gradually going further and then hold and stretch when you have gone as far as possible. If your knees are painful, try putting a pillow between your thigh and calf.



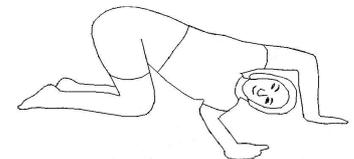
5. SIDE BACK STRETCH

Place both hands to one side (right) and then sit back on your heels (left). Keep your back and shoulders level, avoiding rolling or twisting. Feel a stretch through your side, especially from hip to shoulder. Now repeat with your hands to the left and bottom to the right.



6. CHEST TURN

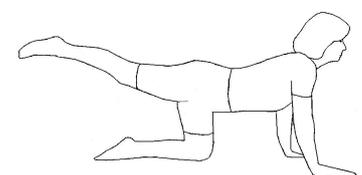
From the four point position—take one arm under your body and the other arm and stretch as far as possible, dropping down onto your shoulder. Look under your other arm, lifting the elbow, turning your upper body as much as possible. Repeat to the other side.

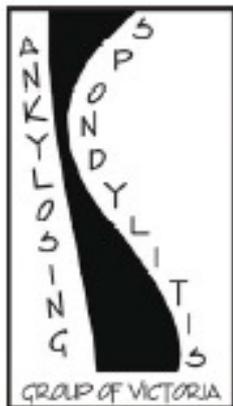


7. CURL and KICK



Bring one knee towards your chest. Look down at this knee. Curl and round your back and the back of your neck. Now stretch this leg out behind you, let your back sag into an arch and look forwards. Repeat with the other leg.





ARTHRITIS VICTORIA NEWS

Over the past couple of months, Arthritis Victoria has addressed two of the main issues resulting from the Policy and Research group's statewide surveys with its

consumers. We commend Arthritis Victoria (ARTH.VIC) on the introduction of the following services for people living with a musculoskeletal condition:

Issue 1: Many people have difficulty accessing and navigating appropriate health-care services and programs in their area.

Resolution: In March 2011, "the **Arthritis Map of Victoria**" was launched by Hon. David Davis, Minister for Health, during Arthritis Awareness week. The online map service was developed in Melbourne by dMap, with funding assistance provided to ARTH.VIC from the Ian Potter Foundation. This is practical interactive tool aims to help people, including those with a musculoskeletal conditions (MSK), in all communities across the state of Victoria, enabling them to quickly locate services and programs they need.

It also displays the latest information on the prevalence of MSK conditions, such as arthritis and osteoporosis, and thus it will be a useful tool for health professionals, researchers and policy makers. The "Arthritis Map of Victoria" is available via the front page of the ARTH.VIC web site www.arthritisvic.org.au.

Issue 2: Access to a rheumatology helpline service to support people with musculoskeletal conditions and health professionals providing healthcare services.

Resolution: In June 2011, Arthritis Victoria launched the **rheumatology**

help line service from their head office in Elsternwick. The service has been made possible with the support of the Victorian Government Department of Health and aims to increase access to accurate evidence based health information. It is available to all Victorians, Monday to Friday PH: **1800 263 265** or email: rhl@arthritisvic.org.au.

The trained nurses providing the service have direct access to rheumatologists at a major tertiary hospital for advice and support as required. The service includes assistance in navigating the complex health, disability and social services systems and a range of community resources available to the caller. The service includes support to health professionals providing care to people with MSK conditions.

At the **annual Arthritis Victoria Consumer Conference** held this year at the William Angliss Institute in Melbourne. A selection of speakers from alternative and complementary medical areas and rheumatologists specialising in particular disciplines or conditions provided over 11 presentations. A cross-section of subjects were covered over the day including diet, pain and fatigue management, complementary therapies, getting motivated with physical activity, Fibromyalgia, Lupus, Gout, Polymyalgia Rheumatica, Rheumatoid Arthritis and Juvenile Arthritis.

In the following section I have highlighted the "take home messages" presented at some of the sessions I attended. Dr. Lesley Braun PhD, Pharmacist, Department of Surgery, Monash University, presented on Complementary Medicines (CMs) and their regulation, quality and alternatives. Using Osteoarthritis and Rheumatoid Arthritis with various CMs as examples, Dr Braun covered the results of a number of clinical trials. The message here was to ensure your healthcare team is informed of the treatments and the CMs is appropriate for your diagnosis, and secondly to be aware they may take some time to be effective. Rocco Di Vincenzo APD, Consultant Dietitian, focused his presentation on "Exploring the potential beneficial

impact of Optimum Nutrition" including various health issues such as the immune system, reducing fatigue /increasing energy and optimising the gastrointestinal function. The example in this case was "How different types of stress impacts our systems" and how possible foods exacerbates the situation. There was a considerable amount of material and great interest in this session.

David Menzies, Fitness Australia, presented an interactive session on motivation and benefits of physical fitness. The message here was about finding what encourages you the most to participate in physical activity and considering it another form of "medication".

I have copies of most of the presentations, full details and titles of the speakers so please contact me if you would like further information. Although it was a very long day from 10:00 am through to 3:30 pm, the attendees I spoke with all found the sessions very informative and the speakers covered most of the queries raised by the audience.

ARTH.VIC should be applauded for conducting an excellent event, very informative speakers and a fitting venue capable of handling the many sessions.

The 37th **Annual General Meeting** of the **Arthritis Foundation of Victoria** was held in late April with the guest speaker Janine Young, the Victorian Public Transport Ombudsman.

It is interesting to note we have two new consumer representatives elected to the board this year, Naomi Creek from Ashburton from the Young Women's Arthritis Group and Janine Fisher from Geelong. It is great to have young and active people involved now at all levels within the organisation representing our consumer base across Victoria.

The **Arthritis Victoria's Volunteer's Celebration and Awards** day was held in May. Linda Martin, the new CEO gave an interesting presentation on motivating volunteers and highlighted some of the

outstanding activities from groups throughout the year.

Our past treasurer, **Rosemary McRae** was mentioned and awarded Outstanding Service Awards however was not able to attend on the day. We will advise on the presentation when firm dates are available.

During May I was invited to run a **community speaker program** session at Melbourne University's, School of Medicine. The brief was to present a "**patient's perspective**" of living with a chronic condition for the Principles of Clinical Practice for first year medical students. I covered the experience of encountering numerous health professionals in the course of managing my chronic condition with a focus on communication, choices of treatment and progress of my AS. This was an interactive session with a small group of 12 students and much time was spent discussing my home, work and social life as a result of the impact of AS.

This exercise was an excellent opportunity to work together directly with the students on subjects they may not experience until well into their working career. ARTH.VIC has been coordinating with a number of Melbourne universities to provide speakers with a MSK to work with students in similar programs.

Here is another example of "**consumer engagement**" in the education/healthcare systems where we can directly contribute. In the AS Group of Victoria article following I have mentioned one of our members, Kevin who also performed this role at the Physiotherapy "AS You See It" Webinar in April.

ANKYLOSING SPONDYLITIS GROUP OF VICTORIA

The last four months have been very hectic for our committee and volunteers with a number of activities, projects and events. Firstly, the committee has sent our congratulations to Rosemary (our former treasurer) and husband Richard McRae with wonderful news of the safe arrival of baby girl Elly, who is certainly keeping Rosemary busy.

Secondly, we have completed another successful year of operation primarily attributable to our past (and present) committee members for their enthusiasm and commitment. Our appreciation is also extended to two new volunteers, Vicky and Sophia for their work with membership and event/media work over the past few months. The year concluded with our **Annual General Meeting** in June, as usual a quiet affair at the Austin Health, attended by committee members and members. The newly elected committee office bearers and members are as follows:

President: Annie McPherson
Secretary: Belinda Martin
Treasurer: Maria Makris
Committee Member -Membership
Co-Ordinator: Vicky Genius
Committee Member -Events
Co-Ordinator: Sophia Koulbanis
Committee Member: Adam Collard
Committee Member: Ellen Makridis

A copy of the minutes have been circulated and the financial records are also available to members. Some of the committee and members moved to the "Old England Hotel" in Heidelberg for an enjoyable relaxed evening, first-rate dinner and catch-up. Thirdly, in the last AStretch edition, Autumn 2011, I mentioned a new member Jon, who joined us for lunch at the hotel in Korumburra. During March, Jon was in contact with me about an exciting project he had in mind for one of our members. Please refer to a later section in this edition for the exciting "Home maintenance project by Ducon Maintenance for Vic and Valmai Walker in Bayles" page12.

Another star performer, was member **Joel Carnegie** who gave an interview about his journey of diagnosis and working life with AS. Jason Berek-Lewis editor of the quarterly Update magazine for Arthritis Victoria where the interview was published commented on Joel's busy life including study, being an active musician and a radio broadcaster. Please look out for this article reproduced in a later edition of AStretch.

Congratulations are due to member **Kevin Yang** for presenting with

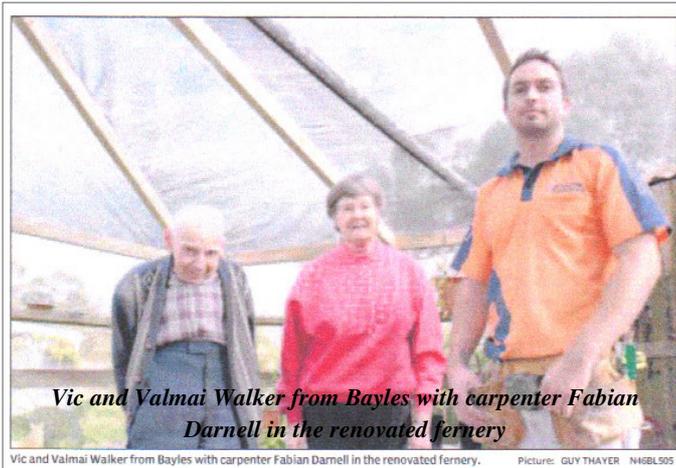
Jennie O'Reilly at the Australian Physiotherapy Association's national Webinar, "AS you see it" in Melbourne in April [*mentioned previously in Margaret Lewingtons' article in this edition*]. The seminar's focus was on AS and other inflammatory arthritis for physiotherapists. Kevin had participated in the Caulfield Community Medical Service's Physiotherapy AS program when Jennie was a leader last year. Jennie and Kevin talked about the patient perspective of living with AS at the Melbourne group. This is a great example of consumer participation in education of health professionals and how we [*in the AS community*] can increase awareness of AS.

Our AS Group of Victoria **membership renewal** form was updated this year and included stamped-self addressed envelopes. We were able to achieve a 70% renewal rate and we wish to thank all those who have renewed. We hope this made it a little easier for members and always value your feedback, comments and suggestions, which help us in managing the group. We are particularly appreciative of those who gave extra time at events and those who sent donations. We always accept memberships throughout the year, just in case you have mislaid the forms, please drop us a line.

Our **Christmas in July** at the Rosstown was held at the end of July. We generally have a good rollup depending on which teams are playing AFL on the night. Even when it is freezing outside, its great to get together and exchange ideas about managing our AS. In October we are planning our annual seminar, and we will advise on dates, speakers and location closer to the time.

Regards to all, Annie McPherson.

A very special project in Bayles for World Spondylitis Day by Annie McPherson



Vic and Valmai Walker from Bayles with carpenter Fabian Darnell in the renovated fernery

Vic and Valmai Walker from Bayles with carpenter Fabian Darnell in the renovated fernery. Picture: GUY THAYER N46BL505



Convoy of tradies at Vic and Valmai's

Ankylosing Spondylitis Group of Victoria

"The home maintenance project for Vic and Valmai Walker organized by Jon Fivet of Ducon Maintenance".

By Annie McPherson

During January 2011, I was contacted by Jon Fivet who had moved to Australia from the United Kingdom. Jon was interested in meeting other people living with Ankylosing Spondylitis (AS) : a debilitating form of arthritis that affects the spine.

Jon has had active AS for about eight years while working full time as a builder and raising a young family. In February of this year, Jon and his family joined members of the AS Vic at an event in Leongatha Gippsland. Attending the lunch provided the opportunity for Jon to meet others living with AS, including one of our long-standing and oldest members Vic and his wife Valmai Walker of Bayles.

Jon had a project in mind, which he had discussed with the directors and a number of the tradesmen contractors, from Ducon Maintenance in Clayton South, the building company where he is Divisional Manager. The company is part of the Ducon Group, a Member of the Master Builders Association. In response to Jon's plans, the company offered to donate time and labour to undertake repairs and maintenance at the home of a person who lives with AS. Our group was delighted and astonished by this generosity.



Vic has been affected by AS for most of his adult life. When I approached Vic and Valmai and told them about Jon's plans, they were really amazed at such generosity and agreed to participate in the pilot project. The project coincided with World Spondylitis Day, held on Saturday 7 May.

We visited the Walker's home, where Jon came up with a list of small jobs that needed to be done including smoke detector replacement, external sensor lights, power points, tap replacements, wardrobe door repairs and general painting. Jon prepared a project plan to determine the hours, tasks and materials required for each group of tradesmen, seven in all, for the project across a work week. The support provided by Ducon Maintenance created an opportunity to increase awareness of AS in the community, particularly among blue collar industries which employ young to middle aged men: a group that is impacted by AS.

Jon's team of smiling tradies arrived at Vic and Valmai's home during the first week of May, with a convoy of vans. The tradies knew all their work was for a very important goal: Vic has not been able to do much home mainte-

nance during the last nine years of his retirement due to his condition. Since Vic retired from his motor mechanic business, after more than 40 years, his limited mobility has allowed him to spend a little time in the vegetable garden with Valmai's help. Valmai's full-time role as carer meant some things just had to wait. So to her amazement, after the first day's schedule of work finished early, the tradies tackled the extra job of making over the fernery with new timber shelves and fresh shade cloth.

We would like to acknowledge the outstanding support of all the tradies: Ducon Maintenance – Glen Owen (Supervisor), Fabian Darnell (Carpenter); BC Painting; Leading Electrical; Dallis Plumbing; Peter Mason and Roger Gribble, the directors of Ducon Maintenance; and NAB and Reece – Pakenham plumbing supplies for their donation of funds for labour and materials. We would like to also acknowledge the support of Arthritis Victoria for their support & encouragement. The success of this project is certainly due to Jon Fivet, the team at Ducon Maintenance, the tradies and their vision of "giving back" to the community.

Welcome to the Qld News.

We are more than half way through the year and last Christmas seems like just the other day. Keeping busy certainly makes the days fly by, but I have trouble sitting around doing nothing. Not only is it boring but also it does nothing for my AS. Whether it is working around the house or garden, riding my Ducati or mountain bike, bushwalking or any other activity that may present itself, I'm there.

My wife and I have recently returned from a trip to China. What a country of contrasts. I was a bit worried about how I would go on the flight over sitting for so long, but with today's wide body aircraft there was plenty of room to move around.

One thing I found was that most of the hotel beds were very hard, which, according to our guide, is apparently how they like them in China. I also had the opportunity to sample some genuine Chinese acupuncture and massage during our Cruise on the Yangtze River. This relieved the pain in my neck and shoulders for quite a few days.

There was plenty of walking during the trip as well as many flights of stairs to climb. I can see how they went through so many workers building The Great Wall of China; just climbing it is hard work far less carrying the millions of bricks up those rugged mountains.

Our June dinner was held at Nero's Restaurant at West End. This was well attended and we all enjoyed a great meal of pasta or pizza with a delicious gelato to finish.

In early May, group member Sharon and myself were invited to speak at a Physio Conference in Brisbane, which was one of a series held around the country to help better equip Physios to manage and assist their patients with AS.

They covered many topics including: early detection, research, drug therapy and the Physio's role. Sharon and I spoke from the patients perspective, sharing our experiences of living with AS. Over 100 Physio's attended and it was also web cast to many more. It is great to see events like this giving



Physio's more knowledge on the subject of AS. Special thanks must go to Abbott for supporting these events.

In other news, it is great to see the PA Hospital's AS Clinic has started its Hydro classes again. For those who attend the clinic this is great news. Hope to see you at one of the upcoming events.

Ross Wilson

DRIVING AND YOUR HEALTH

Your Questions Answered

For most people being able to drive a motor vehicle is a very important part of their daily life – for maintaining social contact, for getting to and from work, and for accessing their everyday needs such as food and services. Driving might also be essential to employment.

But with the benefits of being able to drive also come certain responsibilities and one of these responsibilities is to make sure you are well enough to drive safely.

Certain health conditions can affect your ability to drive safely, either in the short term or more permanently. This brochure explains:

- The types of illnesses that might affect your ability to drive safely.
- Your responsibilities in terms of avoiding driving and notifying the Driver Licensing Authority.
- How your doctor can help you.
- Where you can go for further information and assistance.

What type of health conditions might affect your ability to drive safely?

Driving a motor vehicle is a complex task requiring perception, good judgement, responsiveness and reasonable physical capability. A range of medical conditions, as well as treatments, may therefore impair your driving ability. Common examples include:

- Blackouts or fainting
- Sleep disorders
- Vision problems
- Diabetes
- Epilepsy
- Psychiatric disorders
- Heart disease
- Age-related decline

Just because you have a disease or condition that might affect your driving, doesn't mean that you won't be able to drive at all. It might mean that you have to see your doctor more often to check that your condition is well managed and it might mean that there are some restrictions placed on your driving.

Who makes the rules about whether you are well enough to drive?

The rules about health and driving are developed by medical experts and are agreed to by all Driver Licensing Authorities.



Your doctor does not make the rules but provides advice about how your particular health condition might affect your ability to drive safely and how it might be managed. The Driver Licensing Authority always makes the final decision about your licence status. They will consider the advice of your doctor as well as other factors such as your accident history and the type of vehicle you drive (for example a truck, car or a public passenger vehicle).

What are your legal responsibilities?

All States and Territories in Australia have laws about reporting health conditions that might affect your ability to drive safely. These laws have been created to protect public safety.

The laws require you to report to your Driver Licensing Authority, any permanent or long-term illness that is likely to affect your ability to drive safely.

Your doctor is able to advise you on whether or not you should be reporting a condition to the Driver Licensing Authority. When you report your illness it doesn't necessarily mean that your licence will be taken away. It does mean that the Driver Licensing Authority can work with you and your doctor to manage your condition with respect to your driving.

What if your condition is only temporary?

Many temporary conditions will prevent you from driving. For example, following an anaesthetic your doctor will advise you not to drive for 24 hours or more. An injury, such as a broken leg may also prevent you from driving. In these types of circumstances your doctor will advise you about the need to restrict your driving in the short term. In most cases your licence status will not be affected and you will not need to report to the Driver Licensing Authority.

How will your doctor assess whether or not you should be driving?

When assessing your ability to drive safely, your doctor will consider your physical and psychological health. He or she will refer to a book of medical standards which is used by all doctors throughout Australia and which describes specific requirements for various diseases and conditions. You can view these standards on the internet at:

www.austroads.com.au.

Sometimes it can be difficult to make an assessment and your doctor may refer you for a practical assessment.

What is a conditional licence?

In most cases, having a medical condition will not stop you from driving as the licensing authority is able to issue a conditional licence. This means that you may continue to drive as long as certain conditions or restrictions are met. Conditions may include driving during daylight hours, the wearing of corrective lenses when driving, or attending your doctor for a periodic review and providing a report to the Driver Licensing Authority. Your doctor may make recommendations to the Driver Licensing Authority about a conditional licence but the authority will make the final decision.

If you are issued with a conditional licence it is your responsibility to comply with any driving restrictions or other conditions and to be reviewed by your doctor as required.

Will your doctor notify the Licensing Authority if you are not well enough to drive?

As the relationship between you and your doctor is a confidential one, your doctor will not normally communicate directly with the Driver Licensing Authority. He or she will provide you with advice about your ability to drive safely as well as a letter or report to take to the authority.

Doctors also have an obligation to public safety so your doctor may notify the Driver Licensing Authority directly if he or she feels your condition poses a significant threat to public safety.

What happens if you don't follow your doctor's advice?

If you continue to drive despite your doctor's advice and you do not report your condition to the Driver Licensing Authority, you are not fulfilling your legal responsibility. If you are involved in a crash under these circumstances and it is found that your health condition was a contributing factor, you may be prosecuted and your insurance may not be valid.

If your doctor is aware that you are continuing to drive and feels that your driving is a serious risk to you and other road users, he or she may feel obliged to notify the Driver Licensing Authority directly.

What if you have a licence to drive a commercial vehicle?

Professional drivers such as drivers of trucks, public passenger vehicles and vehicles carrying dangerous goods must meet higher medical standards because of the demands of their work, the extensive hours spent on the road and the serious consequences likely to result from a crash.

If you have an illness that is likely to impact on your ability to drive safely, it is important to tell your doctor what sort of vehicle you drive. It may be that with treatment and regular review you will be able to continue to drive on a conditional licence.

A person who does not meet the health requirements to drive a commercial vehicle may still be eligible to drive a private vehicle.

You are concerned about the safety on the road of a friend or relative. How might you help them?

If you know of licence holders whose health might be affecting their ability to drive safely, it is important to get them to talk to their doctor. It may be that, with appropriate treatment or driving restrictions, they can continue to drive on a conditional licence. Their doctor may also be able to suggest alternative transport solutions. If they are unwilling to discuss this with a doctor, you should contact the Driver Licensing Authority who will deal with the matter confidentially.

Need more information?

See the Austroads website www.austroads.com.au or contact the Driver Licensing Authority in your State or Territory. See contact details below.

Australian Capital Territory

Road User Services, Department of Urban Services
Phone: (02) 6207 7000
Email: roaduserservices@gact.gov.au
Web: www.urbanservices.act.gov.au

New South Wales

Roads and Traffic Authority NSW
Phone: 13 22 13
Email: rta@rta.nsw.gov.au
Web: www.rta.nsw.gov.au

Northern Territory

Department of Infrastructure, Planning & Environment
Phone: 1300 654 628
(08) 8999 3111 (outside NT)
Email: mvr@nt.gov.au
Web: www.ipe.nt.gov.au/dtw

Queensland

Queensland Transport
Phone: 13 23 80 (Local call cost in QLD)
(07) 3215 4500 (outside QLD)
Web: www.transport.qld.gov.au

South Australia

Transport SA
Phone: 13 10 84
Email: licenceservices@transport.sa.gov.au
Web: www.transport.sa.gov.au

Tasmania

Department of Infrastructure Energy & Resources
Phone: 13 11 05
Email: transport@dier.tas.gov.au
Web: www.transport.tas.gov.au

Victoria

VicRoads
Phone: 13 11 71
Email: ccslicence@roads.vic.gov.au
Web: www.vicroads.vic.gov.au

Western Australia

Department for Planning and Infrastructure
Phone: 13 11 56
Web: www.dpi.wa.gov.au

Calendar of Events

Victoria

- **September:** Coffee, Cake and Chat evening at the Fairfield: contact Annie McPherson.
 - **September:** Walk and BBQ at Bayles,
 - **October:** Annual Information Seminar, Austin Health, Heidelberg
- Please contact Belinda Martin PH: 9496 4045 for details

Queensland

- BBQ Sunday 25 September in Rocks Riverside Park Counihan Road, Seventeen Mile Rocks map ref: 198 E3 park and look for the AS banner in the first green area opposite the carpark at 11:00 am. Sausage, basic salad & desert supply. Drinks BYO.

General Information on the web

Spondylitis Association of America

www.spondylitis.org

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

www.nass.co.uk

Ankylosing Spondylitis International Federation (ASIF)

www.spondylitis-international.org

Arthritis Australia

www.arthritisaustralia.com

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

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



Optional Information

(this will help us to provide activities suitable for all members of our group)

Are you a member of Arthritis Victoria? Y / N

Are you happy for us to pass on your contact details to other members of the group in your area? Y / N

Gender M / F

Age Group

- 0 – 20 years
- 21 – 30 years
- 31 – 40 years
- 41 – 50 years
- 51 – 60 years
- 61+ years

Preferred Language

Do you suffer from Ankylosing Spondylitis? Y / N

Do you know someone who suffers from Ankylosing Spondylitis? Y / N

What other conditions do you suffer from?

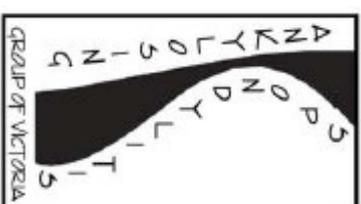
Are there any specific activities you would like us to organise?

Some of the benefits of belonging to our group:

- Quarterly '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

Ankylosing Spondylitis Group of Victoria
PO Box 3166
Burnley North 3121
Contact Belinda on: (03) 9496 4045
Belinda.Martin@austin.org.au

Ankylosing Spondylitis Group of Victoria



Membership Form
Providing education and support
for people
with Ankylosing Spondylitis

