



ASTRETCH

AUTUMN 2014

www.asaustralia.org

ANKYLOSING SPONDYLITIS AUSTRALIA



Ankylosing Spondylitis Symposium *by Greg Johnson and Ross Wilson*

In November of last year, the AS Group of Queensland proudly organised an Ankylosing Spondylitis Symposium which was held at the Translational Research Institute at the Princess Alexandra Hospital. The Symposium was a great success with over 120 attending including people with Ankylosing Spondylitis (AS), their carer's and families, health care professionals and a diverse range of presenters. A variety of AS related health issues and topics were discussed at the Symposium and in future newsletters we intend to bring you a summary of some of the presentations.

Our first presenter was Rheumatologist, **Dr Helen Benham**, who gave an excellent overview of Ankylosing Spondylitis and related Spondyloarthropathy conditions. Dr Benham noted that the prevalence of AS is about 0.5% among the adult population. There is a strong association with a gene called HLA B27 and AS since over 90% of those with AS carry the gene. Only about 1 in 15 people who are HLA

B27 positive go on to develop AS.

The next presenter for the day was **Dr Diana Conrad**, an Ophthalmologist specializing in inflammatory eye conditions. Uveitis affects many people with Ankylosing Spondylitis and Dr Conrad stressed the importance of early diagnosis and treatment. She also stressed checking eye pressure regularly if you are taking drops for or if you have had uveitis. The symptoms for uveitis include:

- Pain in the eye
- Sensitivity to light. Bright light causes the pupil to get smaller causing pain
- Redness and soreness of eye
- Blurred vision

Linda Bradbury, a Rheumatology-Nurse Practitioner who works in the AS Clinic at the Princess Alexandra Hospital and also genetics research with Professor Matthew Brown spoke after morning tea. She discussed management strategies including medication, exercise, healthy diet and how smoking af-

fects the condition. Some interesting correlations for people suffering with AS included:

- Approximately 30% of AS sufferers will develop uveitis
- 10% may develop psoriasis
- 10% may present with an Inflammatory Bowel Disorder e.g. Crohn's disease
- 1% may require an aortic valve replacement

Penny Lewis, a Psychologist, who also has AS, then spoke of strategies for coping with AS. This presentation was very well received as it's an area that isn't commonly spoken about but can play an important part in managing the symptoms of AS. Coping strategies discussed included:

- Cognitive Behaviour Therapy (CBT)
- Mindfulness
- Acceptance and Commitment Therapy
- Positive Therapy

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.

Contents

Ankylosing Spondylitis Symposium	1
Movement for Health	3
A Consensus Statement for Exercise in AS	5
Nick's AS Story	7
AS Exercises	8
Ankylosing Spondylitis Victoria Inc Report	9
AS Group of Qld Report	10
Calendar of Events	11

Contacts

AS Group of Queensland

PO Box 193
TAIGUM
QLD 4018
Ph: 07 3209 6478
E: qld@asaustralia.org

AS Group of Qld is a sub group of Arthritis Qld.

AS Victoria Inc

PO Box 3166
BURNLEY NORTH
VIC 3121
Ph: 0408 343 104
E: asvicweb@gmail.com

Ankylosing Spondylitis Symposium *continued from Page 1*

“Movement for Health” was a very important message that Physiotherapist, **Margaret Lewington** delivered after lunch. She spoke of the importance of combining all forms of movement into your management and exercise plan (please see our article in this newsletter).

Our last presenter for the day was Rheumatologist, **Dr Philip Robinson**, who brought us up to date with the latest research, new treatments and the future for AS management. Dr Robinson discussed outcome measures – does something work and showed how new treatments such as TNF’s were improving patient outcomes significantly. He also mentioned new therapies such as anti IL17 therapy.

The day ended with a panel discussion comprising Margaret, Penny, Philip and Linda who were kept busy with lots of very interesting questions, a few of which research has not yet provided an answer to. One of the aims of the AS Group of Qld is to provide a forum for the exchange of ideas and experiences and this discussion session was a great example of that.

The AS Group of Qld would like to thank all our presenters for volunteering their time to come along and share their

knowledge and experience at our Symposium. Overall it was a great day and our feedback forms suggest that all our attendees went away with a better understanding and increased knowledge of An-

kylosing Spondylitis. We trust this will help them manage their condition and improve the quality of their lives.

Greg Johnson and Ross Wilson



It's time for a stretch and a wave at the AS Symposium!



Lunch and a chat was enjoyed by all!



The Symposium Panel

Michael Russell, Linda Bradbury, Philip Robinson, Penny Lewis and Margaret Lewington answering those tricky questions!

Movement for Health *by Margaret Lewington (Physiotherapist)*

It is important to take every opportunity to move more throughout every day. Only by doing this will you be able to improve your health - many benefits will follow from your effort. Movement that aims to maintain good posture and flexibility helps everyone, even if stiffness and a stooped posture has developed.

Most types of exercise are safe for the majority of people with AS - but caution and care is required in some instances.

The extent of the disease varies widely between people and this makes it important for you to decide what is reasonable for you, preferably in consultation with your physio or health professional.

For those with more severe or advanced disease, it is important to be careful in or avoid contact sports, high impact and strenuous activities. However, those with early disease and little change may have no restrictions - however care is always required.

The most important exercises are those that keep the spine and other joints moving.

It is easy to become a little bit stiffer and a little less upright without being aware of it. It often happens slowly but steadily, unless you check yourself regularly and include specific stretching and mobilising exercises into your routine.

The types of exercises that are needed are the ones that combat the bad effects of AS - stiffness and poor posture. Mobilising exercises help maintain flexibility in the joints, ligaments, muscles and other soft tissues. All areas of the body should be moved and problem areas

as at the time must be targeted most, eg shoulders, hips, mid back, neck etc.

When doing these exercises you need to disregard some discomfort. If the exercise is comfortable, it is not the one that you need to spend a lot of time on. Instead, you need to spend more time on the ones that you find a little difficult and challenging. You need to push yourself out of your comfort zone, if you want to make gains and see improvement.

Strengthening exercises for the muscles that hold you upright and combat the effects of gravity are also essential. This allows you to maintain the gains that you have made with your other exercises.

The aim for people with early AS should be to keep or restore full movement. Those who have more changes or advanced AS may be aiming to keep their existing movement.

Sport and recreational activities are wonderful additions to your physical fitness programme and are an important part of the management of your AS.

General physical fitness provides many benefits to everyone, and not least to the person with AS. As your body becomes more physically conditioned, you become more relaxed and your stamina improves. You gain strength, endurance, flexibility and cardio-vascular fitness. You can also gain improved self esteem and self confidence. It also helps to decrease pain and stiffness. People who become fit tend to want to remain fit. They also tend to place less emphasis on their pain and disability.

It is important for you to see sport and recreation as an enjoyable and fun pastime. While these physical activities are beneficial, they cannot be totally relied upon to ensure an erect posture and flexibility.

It takes time and effort to set the foundations for long term success.

We are all different and have different likes and interests. Hence, choosing an activity is very individual. *The best exercise is the one that you do.*

There is no point telling yourself that you must go to the gym three times a week, if you hate the smell and look of everyone in lycra. Also, if you cannot motivate yourself to get the exercise mat out at home, you need to arrange another strategy.

New Year resolutions are hard to keep, so is a commitment to exercise. They both require *change* - and change is not easy. Adopting a new health behaviour requires a big shift in thinking and doing. Successful change does not happen overnight.

Get started. Do a small amount - just something

Make a plan

Keep your exercise enjoyable

Vary workouts

Calendar of different exercises

Not too much too soon.

Look after yourself - but also do push yourself!

Groups can help in many ways - a time and place to turn up to, as well as lifting mood and helping general wellbeing. Specific AS groups are excellent as support as well, but

Movement for Health *continued from Page 3*

many regular community groups and classes provide good exercise opportunities.

Exercise is such a high priority that you must make time for it every day.

How much exercise do we need? This is a difficult question to answer - It depends on the individual and how your condition is.

In almost every instance, some exercises specific to AS should be done every day. If you are not leading a very active life you will need to do more of them and spend more time on them.

You may be able to make your general exercise and activity achieve some of the stretching goals, and hence achieve two things at once. *The most important thing is consistency.*

The person with AS must believe that an investment of time and energy into an exercise program will translate into a meaningful improvement in outcome. A physiotherapy assessment can help you do this.

This should include AS specific measures, which can then let you know what areas need the most attention for you. It will help you plan an exercise program that is specific to your needs, is what you like, and is effective and efficient. It will ensure that you get the most out of the time you spend exercising.

You should have a physiotherapy assessment at least yearly, and more often if your condition is changing.

Physio's can help you monitor your exercises and activity program. This will give you confidence that you

are doing the exercises well and in the way to achieve the results you need. They can also help with modification to meet any changing needs. Feedback, both in instruction and re-measuring is helpful for motivation to continue to exercise.

Sometimes you may need further physiotherapy - manual techniques, electrotherapy etc. to help relieve pain and improve movement which will help you be able to exercise better and more effectively.

A healthy body leads to a healthy life.

Regardless of what medication you take, it is essential to continue with your AS specific exercise programme.

It has been shown that people on Biologics who continue to do their exercises do better than those who stop. The relief of symptoms that you get when taking biologics should enable you to exercise more. It often provides a window of opportunity to obtain the best possible movement, strength and fitness.

As people often feel such relief when taking the biologics, they often forget to exercise as much. We now often hear 'because I don't hurt as much - I forget to move and stretch.' 'I no longer have the pain reminding me to get up and stretch, to change position, and to do my daily exercises.' The result is sometimes a return of symptoms. The biologic is not enough on its own - we need both.

Exercise is also essential for those with mild disease, and for those managing the condition by taking NSAIDS or no medication. Some evidence shows that exercise helps decrease inflammation. In many

people, they find that when they start a regular exercise programme, they are able to decrease the need for medication.

However, taking adequate medication is important to give you the relief to allow you to move more. Being able to move more freely leads to an increase in incidental movement and activity.

Taking care of yourself is an investment in your own health and also of the people around you. A little 'me' time means better 'you' time later on.

It is not selfish, but quite the opposite. If you don't pay the price of a bit of exercise time now, you will pay a much higher price later on, in increased disability. Engage the support of people around you. - at home, at work, friends. If they see you coping better because you are exercising, they can encourage you to continue. They can exercise with you, they can remind you to exercise or they may just provide you with the time and opportunity to exercise.



Margaret presenting at the Symposium

Set yourself small achievable goals. Remember - regular consistent exercise is essential to keep you moving. It won't be easy - anything worth doing does take effort.

Margaret Lewington

A Consensus Statement for Exercise in AS by Janet Milner (Physiotherapist)

Greetings From Tasmania!

Some newsletter readers may be aware of a project we have been working on for some time now, a **'Consensus Statement' for Exercise in AS in Australia**, and I'd like to take this opportunity to explain a little more about it, Marg has also asked me to report back on the **American College of Rheumatology Conference in San Diego**, which I was able to attend in November last year.

What is a 'Consensus Statement'?

In health literature, it's a review of the available research, by a group who are experts in the topic concerned - who then combine their own knowledge with the written evidence, to produce some practical guidance.

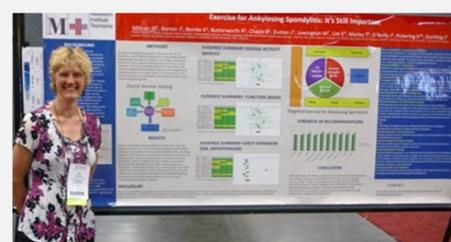
Why do we need one?

As readers of this newsletter would know, regular exercise has long been recommended as part of the ongoing management of ankylosing spondylitis (AS) and associated conditions. There is now quite a large body of research on this topic. But despite this, the existing recommendations are of a general nature only. There has been relatively little research into what specific type of exercise is best, and how often, for how long and how intensely it should be performed. This can leave the person who has AS (and their health professionals) wondering where to start, and just what is the best use of their 'exercise time'.

Who has been involved in the project?

The idea arose at the first meeting of a the Rheumatology Health Professionals Association (RHPA) 'Ankylosing Spondylitis Special Interest Group', which was convened by Marg in Melbourne about three years ago now. The

project took shape slowly at first, with an original group of ten physiotherapists, one of whom has AS. It has been a team effort, with Dr Jane Zochling (a Rheumatologist here is Hobart who has a special interest in AS) and myself acting as co-ordinators for the project.



This poster about the Consensus Statement project was presented at the American College of Rheumatology conference in San Diego late last year (see below)

How have the recommendations been developed?

This has been a lengthy process, where we aim to combine a scientific approach to analysing the research, with the clinical experience and opinion of the group. Basically, we independently generated 'clinical questions' about exercise in AS, and these were grouped into eight topic areas as follows:

- Assessment/ monitoring for exercise
- Safety
- Disease Modification
- AS-specific exercise
- Physical Activity
- Exercise Setting
- Dosage
- Compliance

A systematic (pre-planned) review of the literature was carried out for each topic area, and the clinical trials assessed for their quality and relevance to the exercise options we have here in Australia (many studies are based in European spa facilities!). At a face to

face meeting of the group in Sydney, the evidence for each topic was presented, and ten recommendations developed. We later 'tested' these recommendations further, in the form an electronic survey, and now we are completing the scientific write-up of the project.

What is the evidence base for the recommendations?

We found (and read!) over 394 articles that related to exercise and AS, choosing the best level of evidence available for each of the topics. This resulted in a real 'mixed bag' of evidence in scientific terms, from the 'best' (combined results of several good quality trials) through to lower quality trials, surveys and our own experience/ opinion. The good news is, there is high 'Level 1' evidence that exercise for AS is beneficial, and more so than for other conditions. However, in other areas the science is less strong and that's where the combined knowledge of the group has been so valuable.

What input has there been from people with AS, and other health professionals?

As mentioned above, one of the writing group has AS, and we gained more useful information via 'Survey Monkey' – so a **big 'thank you' to all those that completed the survey** – your input was appreciated and helpful. We were impressed by the enthusiasm for the project, receiving 90 completed responses from patients, with representation from all the states and territories. We found that all of the recommendations appeared well supported by people with AS and other health professionals, and hope that we may publish some of the helpful comments/ feedback online at a future date.

A Consensus Statement for Exercise in AS *continued from Page 5*

What has been the most surprising finding of the recommendations?

Of course, to those who have lived or worked with the condition for a while, many of the recommendations may simply reinforce what you already know. However, they are really aimed at those health professionals and individuals who don't necessarily have that experience. The bottom line is that exercise works – but only if you do it! Like the rest of the population, many people with AS don't exercise regularly, hence the writing group found the sections on 'Dosage' and 'Compliance' to be particularly challenging - and worthy of more research in the future.



When will the Consensus Statement be published?

The short answer is soon – we hope! We've already gained further valuable feedback following presentations at two conferences in Australia, and one in America. The scientific paper is in its final stages of being written, and after review by the whole group will be submitted for publication in an arthritis journal. This is a long process but it's important to be thorough in order for the recommendations to be credible. We plan to make it an 'open access' publication, which means that anyone will be able to view it without

charge. At that stage, we'll also be able to broadcast the recommendations more widely.....

And now to San Diego.....

I was fortunate to be able to attend the Annual Meeting of the American College of Rheumatology and Association of Rheumatology Health Professionals in San Diego, and to present a poster about the Consensus Statement there. This conference is the largest for rheumatology in the world, with everything on a grand scale – just finding your way around the venues takes some time! Attending the conference itself is something of a test of stamina, with many concurrent sessions, which include invited speakers from around the world, and many (like us) who submitted an abstract to be selected for a poster or oral presentation – there were 2940 in this category! In addition, there is an industry/ consumer group exhibition, networking events and study groups, all continually happening from 7.30 am until 6.30 pm each day.

The sessions on AS appeared well attended and the themes I picked up on included: ongoing work on defining the various forms of 'Spondyloarthritis' and their relationship to each other; how these may be differentiated from other forms of back pain, and how to improve diagnosis, and thus begin treatment earlier. Our poster had a good spot in the huge hall, and I enjoyed answering many questions on the work we had done. Nearby were other health professionals also working in this area (mainly from Scandinavia), so it was a great opportunity to exchange ideas on our respective research interests.

Of course, some exercise was required to counteract all that sitting down at the conference (after all, exercise works.....), so I hired a lovely shiny red

bicycle and got mine by exploring the cycle trails round San Diego....



Pedal power was a great way to see San Diego – this is Bilboa Park, just north of the city.

About the Author:

Janet Millner is a Physiotherapist with a long-standing interest in Ankylosing Spondylitis and associated conditions. Currently she is the Clinical Lead Physiotherapist for Rheumatology at the Royal Hobart Hospital, and is studying for a Masters degree by medical research at the Menzies Research Institute, Hobart, as part of the Tasmanian Ankylosing Spondylitis Study headed by Dr Jane Zochling.

Acknowledgement:

The author would like to acknowledge and thank AbbVie Pty Ltd for providing logistical support for a group meeting to develop the recommendations. AbbVie Pty Ltd funded Cutting Edge Services, Sydney, Australia who provided logistical services for this meeting, and AbbVie Pty Ltd reimbursed travel expenses for meeting attendees. AbbVie Pty Ltd was not involved in the development or review of this publication.

Nick's AS Story *by Nicola Boemo*

After 10 months of cruising his way around America's coastlines, exploring the depths of Europe's cobblestones and trekking through Asian jungles Nick finally made it safely back home to Melbourne. An incredible gap year of travelling opened his eyes to the sheer heights life can take you. Nick came home with incredible memories and some outrageous stories, but he also came home to face a diagnosis no one should ever have to face, especially at 19 years of age.

After months of tiresome medical appointments with doctors struggling to provide Nick and his family with solid answers as to why he was feeling stabbing joint pain, he was able to rule out common conditions such as Reactive Arthritis and Lyme Disease. With various specialist visits, steroid injections and a continuous emotional struggle to figure out what it was exactly causing his unbearable joint pain, Nick was finally diagnosed with Ankylosing Spondylitis.

"Ankle spondy what?" everyone would ask. Trying to pronounce the tongue twister let alone come to terms with the fact that he was now part of the 2% of Australians affected by this rare incurable disease was difficult enough. Six months on and Nick's excruciating pain in his lower back showed no sign of improving and when swelling in his fingers and toes arose, life really seemed to tumble downwards. Like many AS sufferers Nick physically struggled to get out of bed in the mornings, only to look forward to a handful of drugs everyday in order to get some sort of mobility back before he could consider starting another agonizing day at work. Even though Nick never let anything stop him from living life

to the fullest, living with AS was a definite struggle.

His sheer determination and 'suck it up' attitude was the envy of all his friends and family. Nick turned to exercise as his safe haven. Keeping fit and active

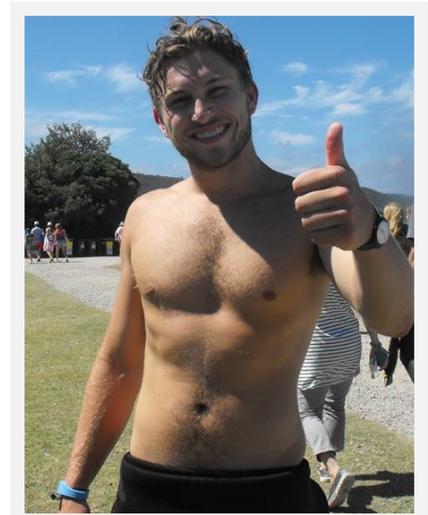
**"ANKLE SPONDY
WHAT?"
EVERYONE
WOULD ASK.**

had always been a passion of his, now so more than ever. Regular laps of the 50m local outdoor pool (even on those frosty winter mornings!) gave him the kick-start he needed. All the experts say physical activity helps to increase mobility for those suffering from AS, but for Nick it helped him in a different way. "When I am active, it helps to distract me from my everyday aches and pains and makes me feel as though I am still keeping up with my normal life, a life full of good friendship and laughter." Drugs would help mask some of the pain, but regular physical activity alleviated the stiffness of his joints allowing Nick to keep shredding the slopes in New Zealand and longboarding along the beaches of Portsea.

Many of Nick's friends had absolutely no idea he was suffering from such a draining disease, he never considered it necessary for everyone to fuss about him. With so few Australian AS charities and very little public awareness of the condition, it was often hard for Nick's friends and family to sympathise for him. With this in mind, Nick took it upon himself to educate the people around him through a very special and personal approach.

One year on from his diagnosis, Nick participated in the 34th GMHBA Lorne Pier To Pub this January, where 5,000

participants swam 1.2km across open water from the Lorne Pier to the shores of the Pub. Through the help of social media, Nick raised awareness of AS and having reached his first fundraising goal of \$700 within just 3 hours, he bumped the target up to \$3,000. With one hour until the starting gun was fired, he had reach \$3,102. Finishing the race in 16.31minutes, the vibes at Lorne were pumping! The enormous generosity showed what incredible support he has around him with all the funds being donated to Arthritis Australia, specifically towards the research of AS.



Nick wanted to prove not only to himself, but also to everyone around him that AS doesn't have to put your life to a halt. Competing in the Lorne Pier to Pub gave him his confidence back and assured him that even though he will live with AS for the rest of his life, he is still capable of achieving great things. With the support and relief from a new drug Simponi, Nick is currently backpacking through Mexican cactus plantations and scuba diving in the Caribbean, he has registered for the Melbourne Marathon this October and has great visions for an AS Charity Gala. He hopes that his efforts provide support and reassurance for other AS sufferers out there that pain can be conquered.

Nicola Boemo

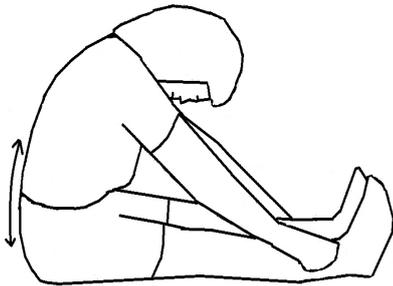
AS Exercises by Margaret Lewington (Physiotherapist)

This issue features a series of exercises done in long sitting - legs out in front and knees as straight as possible. If you are not able to straighten your knees, you may wish to put a pillow under them so as they feel more relaxed. These exercises are mostly for stretching - trying to go a little further - hence they should be done slowly, but sometimes some small movement helps to get that bit further.

Remember to BREATHE!

1. Forward Stretch

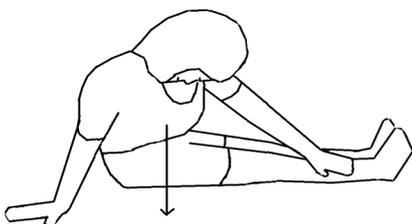
Sit on the floor, legs as straight as possible in front. Lean forwards at the hips, reaching towards your ankles. Go as far as you can, then hold your legs. Try to feel a stretch from your buttocks up your whole back and let your head look down.



Hold this position, breathe and relax. You may then be able to go a little further reaching closer to your feet. For extra stretch, push your heels away (toes up). In this position while you feel the stretch, you can lift your head up and down a few times, and then stretch more. Also, you can move your feet up and down and then stretch more. This will then stretch all the soft tissues from your feet to your head.

2. Forward Stretch Turn

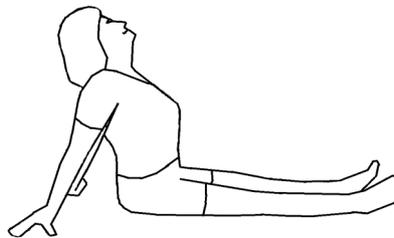
This is similar to the above, but with a small turn. Place one hand on your oppo-



site knee and the other hand on the floor near your hip. Use your arms to help you turn to the side and then bend forward, taking your chest down towards the floor beside your hip. Breathe and stretch a little more. You can do the same movements of lifting and dropping your head followed by an extra stretch.

3. Arch Up

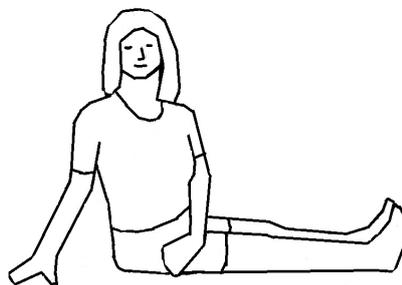
Place your hands on the floor behind you. Lift your chest and head. This will arch your back, both the low and upper parts.



Do not take your head too far back, keep it in line with your chest.

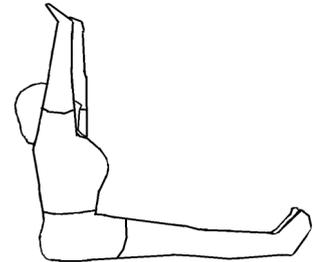
4. Sit Tall and Turn

Place one hand on your opposite thigh and the other one on the floor behind your hip. Keep your chest tall and pull with your arms to turn your trunk to look behind.



Do not slouch. Turn your head as much as possible as well. Breathe, relax and try to go a little further. Repeat several times and then turn to the other side.

5. Reach and look up



Sit tall, chest up and look up. Then reach up with your arms as far as possible. Stretch and reach tall. Breathe in and keep tall as you breathe out.

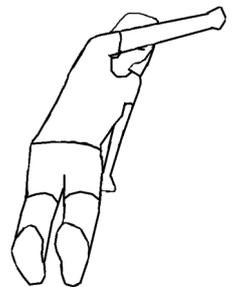
6. Side Bend

Sit tall, place your left hand on the floor beside your hip to give you support and to help keep both buttocks on the floor (you may even roll your hips slightly to the right). Take your right arm over your head to the side - stretching up and across. Avoid bringing your arm in front of your face. Feel a stretch through the whole of your right side - above the hip, through the ribs, under the shoulder and along the arm. Breathe and feel the ribs separate/open for extra stretch.



7. Diagonal Forward Reach

Sit tall, turn your body towards the left side. With your right arm, reach or punch forwards and up - across your body towards the left. Do several times, then swap sides. You may like to pull back with your left elbow as you punch to help you turn more.



Ankylosing Spondylitis Victoria Inc Report *by Annie McPherson*

February, 2013

December and January are usually quiet months for our group with most folks enjoying the holidays and having children round about more than usual. So we have not had a lot of group activity. It is extra tricky to try and stick to our usual exercise routines and with the extreme heat we have had – even tougher. I have tried every indoor activity from ironing and vacuuming to playing with the Sandy my cat to keep moving about whilst avoiding the heat. At last now towards the end of February we can enjoy cooler nights and mornings and some outdoor activity.

At our AS Victoria Inc. committee meeting on Tuesday 11 February we welcomed member Claire McLinden to the office of Secretary. Claire is studying law at LaTrobe University. She has experience in Secretary work and volunteering for not for profit groups in Australia and in the UK for a health industry regulator. The position became vacant following Maria Makris decisions to step back from her role as Secretary. Maria who is a founding member of our group will continue as a committee member. We have thanked Maria for her various officer roles over the past years and for her ongoing commitment and support for the committee.

Our February Rose Hotel dinner had a good turnout of members and new members, Kath, Paul and Diane, joining our group. There was plenty of discussion and ideas about the table and Claire picked up a lot on how we manage our condition. We also had a lovely surprise from a member who introduced us to her new baby, just 2 and a bit months old, all doing very well and happy. We would also like to extend a warm welcome to new members Rob, Patricia, Chris, and Chelsea who have joined us since our last Astretch edition.

During November 2013 I was contacted by Nicola on behalf of her friend Nick who had been recently diagnosed with AS. They had decided to participate in the “Pier-to-Pub” annual ocean swim event on the Great Ocean Road seaside town of Lorne in Victoria in January 2014. Nicola has kindly put their story together with some photos and you can read about it in this edition of Astretch. We would like to congratulate them on a terrific fundraising effort for research into AS.

Keep an eye out on our web site www.asvictoria.org for our planned event on World Spondylitis Day – Saturday 03 May 2014.

Caulfield Community Health Service Ankylosing Spondylitis Course

Physiotherapy, hydrotherapy, group exercises and education for people with Ankylosing Spondylitis

Enquiries: 03 9076 6804 - Belinda Coulter
31 March to 26 May, 2014 – Monday Evenings

GP referral & physio assessment required

Cost \$120 plus a physio assessment fee (dependent on health card level). Program is run twice per year.

Arthritis & Osteoporosis Victoria news:

Community Speaker work: In February I attended the Foundation Week, Patient Perspective presentations to the first year students at the Medical School, Melbourne University. There were three speakers at each session talking about arthritis and cystic fibrosis and covered our experiences in the healthcare industry over many years of managing a chronic condition and a

lively question and answer time ensued. As always each of the speakers emphasised how important it was for patients to have good communications with our health professionals to achieve the best possible management of our various conditions.

This year for 2014 Arthritis Awareness week 23 – 29 March we have arranged an AS Information table at the Austin Health, Repatriation Campus, Tobruk Centre, Banksia Street, Heidelberg. The table will be set up with AS fact sheets, Astretch newsletters, booklets and related information on Tuesday 25 March on the same day as the Rheumatology and AS Clinics in the Outpatients Department. We hope to have a visit from Noel Smith who is now an Ambassador for Arth.& Osteop. Vic and a consumer representative on the Austin Health Consumer Advisory Committee. I have known Noel for over 15 years as he has been active in the warm water exercise classes and consumer representative areas for Arth.& Osteop. Vic.

Earlier in the Arthritis Awareness week our representatives will be attending the Arth. & Osteop. Vic, peer support group leaders function where we catch up with other groups like the Korumburra and Warrigal groups. Next year we hope to have some joint functions with these groups in the Gippsland region.

We hope to see you at our next event,

Keep well and active,

Annie McPherson



AS Group of Queensland Report *by Ross Wilson*

May I start by wishing everybody a Happy New Year, although it is a bit late as we are fast approaching Easter. I hope you all had a great Christmas break and are tackling the New Year with plenty of enthusiasm.

We have taken the opportunity in this newsletter to highlight the Symposium that the AS Group of Qld hosted in November of last year. Our group was established to support you, the people living with AS, and your families and also to promote awareness to the wider medical community and in doing so help bring about earlier diagnosis. Our aim is to give you the information to learn and the opportunities to meet others travelling the same journey. This newsletter, land and water exercise DVD's and guidebooks etc. are some of the things we provide.

We are planning to have a wide variety of social event this year, starting with a Nordic Walking class, which should be interesting. Once

again if anyone has ideas for events please let us know and we will try and make it happen.

There is an international event which everyone is invited to join called "Walk your AS off". The Queensland Group has a team already up and running which you are welcome to join or you can start your own. It runs from the 1st March to the 3rd May, which is World Spondylitis Day. The details are included in this Newsletter (see below). Please consider being a part of it.

Our Christmas dinner was once again well attended with a great group enjoying some good food and wine at Avanti Café at Bardon. Although the weather looked threatening as we drove there, we missed the worst of it, which was good. By the time we were ready to leave it had turned into a beautiful evening.

It is almost time for our Annual General Meeting again, so please think about coming along. More



Ross delivering the AS Group of Qld aims at the Symposium

information will be sent in the coming weeks.

I look forward to crossing paths with you all in the coming year.

Ross Wilson
President

Walk Your A.S. Off

Taking steps for Spondylitis Awareness, Health & Research for a CURE!
2014 Walk Begins March 1st!

[Walk your AS Off Group of Queensland](#)

Walk Your A.S. Off is a community based campaign held each year from March 1st until World AS Day. We walk to raise awareness of Ankylosing Spondylitis (AS) and the family of related diseases. We walk where we live and work without the need to attend any events. We track our daily steps and set large collective goals. Our walk brings people & teams together from all over the globe, showing that a small group of people can take great strides to change the world. See www.walkyourasoff.com



Calendar of Events

VICTORIA

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

March 11, Tuesday : Fairfield RSL – Coffee & Chat night

March 23 – 30 : Arthritis Awareness Week

May 03, Saturday: World Spondylitis Day (to be advised)

May 20, Tuesday: Fairfield RSL – Coffee & Chat night

Please also check Arthritis & Osteoporosis Vic. website for events www.arthritisvic.org

QUEENSLAND

Refer to www.asaustralia.org/qld/ for details or Mark Robinson mob: 0407 425 750 or Marg 0404 414 501

Saturday, March 8th: Nordic Walking Experience

Venue: Gasworks
76 Skyring Tce, NEWSTEAD

Time: 5.00 - 6:30pm

Clothes: Comfortable loose clothing and shoes. Nordic poles supplied.

Cost: \$10 (places limited)

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: \$10 or 10 classes for \$90

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 5:30 - 6:30pm.

Gymnasium & pool 5:45 - 7:45pm.

For those current group members and those who have recently participated in an AS program with the Hospital or the Arthritis Foundation.

Where: Royal Perth Rehabilitation Hospital,

Shenton Park Annexe, Selby St,
SHENTON PARK.

Cost: \$8

Enquiries: Lindsay 08 9382 7307



**AS Brisbane has a
Facebook Group!!**

General Information

Ankylosing Spondylitis Groups of Australia

www.asaustralia.org

Ankylosing Spondylitis Victoria Inc

www.asvictoria.org

Arthritis Australia

www.arthritisaustralia.com.au

Spondylitis Association of America (SAA)

www.spondylitis.org

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

Ankylosing Spondylitis International Federation (ASIF)

www.spondylitis-international.org

The National Ankylosing Spondylitis Society (NASS - United Kingdom)

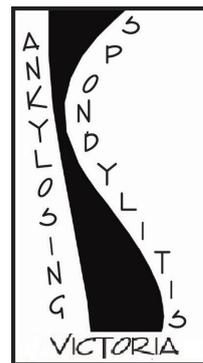
www.nass.co.uk

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

Ankylosing Spondylitis Victoria Inc

Membership Form

AS Victoria Inc is an Arthritis and Osteoporosis Victoria 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.au

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)

Donation: \$ _____

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?

.....

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.