

A Stretch

Ankylosing Spondylitis Australia

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Ankylosing Spondylitis Patients Need Special Care

Bryan Bledsoe, D.O.



Bryan Bledsoe D.O.

This Article reprinted from Spondylitis Plus Fall 2006 edition, first appeared in JEMS (Journal of Emergency Medicine) U.S.A in July 2006.

In a small town in Indiana a man collapses, and EMS is summoned. When paramedics arrive, they find the man in cardiac arrest. So, based on their education and experience, they begin resuscitative measures. Per protocol, they elect to place an endotracheal (ET) tube. During the process of intubation, they extend the head to properly visualize the airway. Unfortunately, they hear a "crack". The patient's cervical spine is fractured and the spinal cord injured. The paramedics did not do anything wrong; they followed established protocols. But the patient suffered from a condition called ankylosing spondylitis (AS), a condition that requires care modifications.

An estimated 500,000 people in the United States have AS, a form of inflammatory arthritis that primarily affects the spine. The disease causes inflammation of the joints between the vertebrae of the spine and the sacroiliac joints in the pelvis. It can also cause inflammation and pain in other parts of the body. As the condition worsens and the inflammation persists, new bone forms as a part of the healing process. The bone may grow from the edge of the vertebra across the disc space between two vertebra, resulting in a bony bridge. This may occur throughout the spine so that the spine may become stiff and inflexible, effectively fusing the spine. On spinal X-rays, this phenomenon is referred to as bamboo spine. This fusion can also affect the rib cage, restricting lung capacity and function.

As the disease progresses, the spine can become fused into a single unit incapable of flexion, extension or lateral movement. Usually, the fusion progresses with the spine assuming a flexed position and the patient forced to walk

bent over. EMS providers called to care for a victim of AS must remember that their patient's spine is inflexible and cannot be moved. Further, the fused spine can be extremely fragile and subject to fracture with resultant spinal cord injury. Numerous EMS techniques must be modified to accommodate patients with AS. These include airway management techniques, splinting techniques and transport considerations. Because most AS patients have spinal flexion, it's important to adequately pad underneath the patient's head, neck and upper back with a pillow or pillows. Likewise, airway management techniques must be applied without extending the neck. Airway devices that do not require visualization (e.g. CombiTube, LMA) should be considered instead of ET intubation, with cricothyrotomy used as a last resort.

Although AS is not common, improper EMS care of patients with the disease can be devastating. Learn to identify the signs and symptoms of AS, and protect the spine accordingly.

Learn more at online at:
www.spondylitis.org/about/main.aspx.

Acknowledgements: Thank you to Bryan E. Bledsoe, DO, FACEP, for writing this article. It originally appeared in the Journal of Emergency Medical Services (JEMS); July 2006



When ever possible, please alert medical personnel of your condition as a patient with Spondylitis so you get the proper medical attention, regardless if the situation is A.S. related.

Cigarette Smoking and Ankylosing Spondylitis

Professor Matthew Brown

Princess Alexandra Hospital, Brisbane



Many people, most of them smokers, will not read this article further than this because they think they've heard it all before. Patience please! If you have AS and smoke, you really need to think hard about giving up, even more than people without AS. The reason is because there are many factors peculiar to AS that smoking detrimentally affects.

Why write this article now? Because we have just analysed the data from the first 6 months of our AS Specialist Clinic in Brisbane, and the standout finding was that AS patients who smoke had far worse disease activity than those that didn't, with a mean Bath Ankylosing Spondylitis Disease Activity Index which was 50% worse than non-smokers. That's a huge difference. To put it into perspective, taking NSAIDs improves this score by less than this.

What are the effects of smoking in AS?

- Smokers are more likely to develop AS.
- AS is associated with a 50% increase in mortality rate compared with age- and gender- matched people without AS, mostly due to cardiovascular disease. Smoking will exacerbate this.
- AS is commonly associated with lung disease. In a recent study 40% of AS patients were found to have significant lung abnormalities on close examination. Also, because AS leads to restriction of chest wall movement due to fusion of the thoracic spine and rib joints, AS patients have less respiratory 'reserve' than those without AS. So if you smoke and do even more harm to your lungs, then you will develop respiratory failure much faster than people without AS..
- AS commonly causes osteoporosis. People who smoke are twice as likely to develop hip fractures than those who don't, so why add another risk on top of the risk you have with your AS anyway?
- Smoking is associated with stomach ulcers. AS patients are at increased risk anyway of stomach ulceration through NSAID usage.

So smoking just adds another risk.

- If you get smoking-induced chronic bronchitis, you may be excluded from receiving TNF-blocker treatments, which are extremely effective in AS.

There are lots of other reasons why you shouldn't smoke which apply generally and are not specific to AS, such as:

- It causes a wide range of cancers
- It causes heart attacks, strokes and peripheral vascular disease (leading sometimes to the need for amputations)
- It costs a lot of money
- It makes you smell bad.

So what can you do to stop smoking? First, decide to quit. Second, get some help.

Where from? Try :-

1. Your GP, and
2. The Queensland Cancer Fund (http://www.qldcancer.com.au/reduce_risk/prevention/Stepstoquit.asp, or call the Quitline 13 QUIT (13 7848)).

The Queensland Cancer Fund advise:

- Set a date to quit. Choose a date when there will be a low amount of pressure on you, two to three weeks from now.
- Plan for the most risky times. Plan activities that will not expose you to situations where you will be tempted to smoke.
- Enlist the support of your friends and family.
- Hold a clean up ritual. Clean cigarettes out of your car, handbag, briefcase and house. Get rid of ashtrays and lighters.
- Think of yourself as a non-smoker from the moment you quit.
- Understand withdrawal symptoms. These are the reactions that your body may experience as it flushes itself of nicotine and other chemicals. Think of these as recovery symptoms. Some recovery symptoms will come and go over a period of a few days, and most are gone within two to three weeks. Emotional symptoms, such as anxiety and irritability, are closely tied to the physical reaction of your body as the nicotine leaves your system.
- Remember the 4Ds.
- Delay acting on the urge to smoke. After five minutes, the urge to smoke weakens and your resolve to quit will come back.

- Deep breathe. Take a long slow breath in and slowly out again. Repeat three times.
- Drink water.
- Do something else. Take your mind off smoking by taking action.
- Reward yourself. Put aside the money you would have spent on cigarettes in a jar – you may be surprised by the amount you can save.
- Remember, having 'just one' will hurt. This is the way that most people go back to smoking.
- If you have a relapse, don't despair and don't give up on your plans to quit. Most people who have successfully quit smoking for good have made several serious attempts. Everyday that you have spent smoke free makes your body healthier and helps break your habit and weaken your addiction.

Do something to help yourself.

Stop smoking!

MATT BROWN

AS SPECIALIST CLINIC

Professor Matthew Brown's group at Princess Alexandra Hospital have started a weekly specialist clinic solely for patients with ankylosing spondylitis. The aim of the clinic is to provide comprehensive medical, physiotherapy and nursing care to patients with AS.

To organise to attend the clinic patients will need a referral from their GP or rheumatologist. These should be sent to:

Linda Bradbury,
Ankylosing Spondylitis
Specialist Clinic,
Level 4, Centre for Immunology
and Cancer Research,
Princess Alexandra Hospital,
Ipswich Road,
Woolloongabba, Qld, 4102.

If you would like more information about the clinic, Linda Bradbury (Research Nurse) can be contacted on 07 3240 5999.

Soundbites in Rheumatology from the Spondylitis Association of America Spondylitis Plus Magazine Fall (Autumn) 2006 issue

Disease and Psychological Status in Ankylosing Spondylitis

Authors: J. Martindale, J. Smith, C.I. Sutton, D. Grennan, L. Goodacre and J. A. Goodacre.

Ref Rheumatology Advance Access published April 4, 2006

Objectives: In this study, the researchers set out with two main objectives.

To describe the association between disease and psychological status in AS, employing AS-specific tools and questionnaires, and then, to determine whether the assumptions generated by the study would remain stable over time.

Method: In this Study, a total of 110 patients with AS were assessed at six-month intervals, up to four times, using tools to measure disease activity.

Results: Eighty-nine participants completed all four assessments. The researchers were able to determine that those patients who were clinically anxious or depressed had significantly worse clinical outcome in disease activity and ability to function. The mean scores for disease, psychological and health status proved to be clinically stable over time.

Conclusion: Disease status scores in AS correlated significantly with anxiety, depression, general well-being (internality), and health status. It was concluded that these findings have important potential applications in the management of AS and may even play a role in identifying candidate patients for biological therapies.

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Bone Density, Ultrasound Measurement and Body Composition in Early Ankylosing Spondylitis

Authors: F. Toussiro, F. Michel and D. Wendling

Ref. Rheumatology 20001;40:882-888

Objectives: Patients with AS were evaluated for bone mineral density (BMD) using two different types of Measurement devices: dual-energy X-ray absorptiometry (DEXA); and quantitative ultrasound (QUS).

Method: Seventy-one patients with AS were compared to seventy-one sex and age-matched controls. Each person underwent an extensive physical exam, which included BMD of the lumbar spine and femoral neck, total body measurements were performed, including bone mineral content (BMC) of the whole body, fat and lean masses. Broadband ultrasound (BUA) was used to measure stiffness of various aspects of the skeleton, and the heel bone (calcaneus) was examined using an Achilles ultra-sound device.

Results: According to the researchers, the patients showed significant differences and lower BMD of the lower spine, femoral neck and total body when compared to unaffected people in the study. Fat and lean mass turned out to be just about the same in both groups.

Conclusion: The results of this study confirmed that AS patients have decreased BMD values, reflecting a generalized bone loss. On the contrary, soft tissue does not seem to be impacted by the disease. The study did not support the use of QUS as an adjunct tool to DEXA in measuring bone loss in people with AS.

§§§§§

Childhood-onset Arthritis Linked to Increased Risk of Fracture *Ann Rheum Dis* 2006;65:1074-1079

According to a recent report from Reuters Health, people with childhood onset arthritis have a significantly increased risk of bone fracture in childhood, adolescence and it has been suggested in adulthood.

Dr. Jon Michael Burnham and colleagues, Children's Hospital, Philadelphia, Penn., identified 1,939 individuals who had been diagnosed with childhood onset arthritis, between the ages of one and nineteen years of age.

The researchers found that there was a significantly higher incidence of bone fracture, particularly in the arms and legs of the patients with juvenile onset of rheumatic disease.

From the results of this study, Dr. Burnham and his colleagues deduced that it is critical for children with arthritis

to be monitored thoroughly, and for the arthritis to be well controlled. They also suggested that the immobility associated with active arthritis may exacerbate the already known recognized complication of osteoporosis related to childhood arthritis.



Goals of Ankylosing Spondylitis Patient Organisations

Lecture held at the 2nd Congress of the Turkish Rheumatology Association, Antalya 29 April 2006, by Ernst Feldtkeller, Munich, Ankylosing Spondylitis International Federation (ASIF) Vice president

In 1973, Danish patients with ankylosing spondylitis (AS) were the first to found an ankylosing-spondylitis-specific patient organisation. Patients in other countries followed. In 1988 we founded a common international network called Ankylosing Spondylitis International Federation (ASIF). Members of ASIF are now organisations in 25 countries listed here, with a total membership of about 48 000 patients (Figure 1).

country	founded in	patient members	physiotherapy groups
Denmark	1973	≈ 1 060	10
Great Britain	1976	≈ 6 800	104
Switzerland	1978	≈ 2 650	82
Germany	1980	15 353	437
Hungary	1981	≈ 700	6
Portugal	1982	≈ 1 520	11
USA	1983	≈ 5 300	0
Slovenia	1983	≈ 2 300	14
Belgium/Flanders	1983	≈ 740	16
Austria	1984	1 190	46
Canada (3 Prov.)	1984-90	464	1
Norway	1986	≈ 2 300	13
Ireland	1986	≈ 120	1
Italy	1987	562	2
Czechia	1990	1 790	14
Singapore	1990	147	1
Croatia	1991	≈ 334	6
Japan	1991	1 260	0
Spain	1992-1996	1 610	17
Iran	1993	610	1
Australia/Queensland	1996	88	1
Taiwan	1996	≈ 700	1
France	2000	1135	6
Turkey	2003	50	3
Brazil	2004	74	1

Figure 1. ASIF member societies in their order of foundation

Detailed information on these AS organisations, their actual addresses, phone and fax numbers and internet addresses, as well as the responsible persons, published literature may be found in the ASIF Internet website under the address

► www.spondylitis-international.org

An important goal of these and similar disease-specific patient organisations is to contribute to physical and mental health of patients by

- organizing weekly disease-specific group physiotherapy,
- opposing the social isolation of patients,
- facilitating the exchange of experiences among patients,
- advising patients in social and medical problems,
- making available information on the disease,
- representing the interests of patients in public and legislation, and
- increasing public awareness of the disease.

Another important goal is to promote and encourage scientific research on the

disease and to make research results public to the patients concerned. How these goals are achieved, is described in the following.

Weekly disease-specific group physiotherapy

The disease outcome can be influenced essentially by careful position self-control and by regular exercises. For exercising at home every day, much self-discipline is however necessary. In this respect, the weekly disease-specific group therapy is a valuable help and source of motivation. A network of groups – with less than 50 km average distance – is now offering weekly AS-specific physiotherapy in Great Britain, Flanders, Germany, Switzerland, Austria, and in Slovenia.

Common sports favourable for AS

Practising favourable sports also belongs to the program of many local branches of our organisations. Preferred sports practised within AS groups are

- Volley ball with regulations adapted to the condition,
- Cross country skiing,
- Nordic Walking,
- and Swimming in warm water.

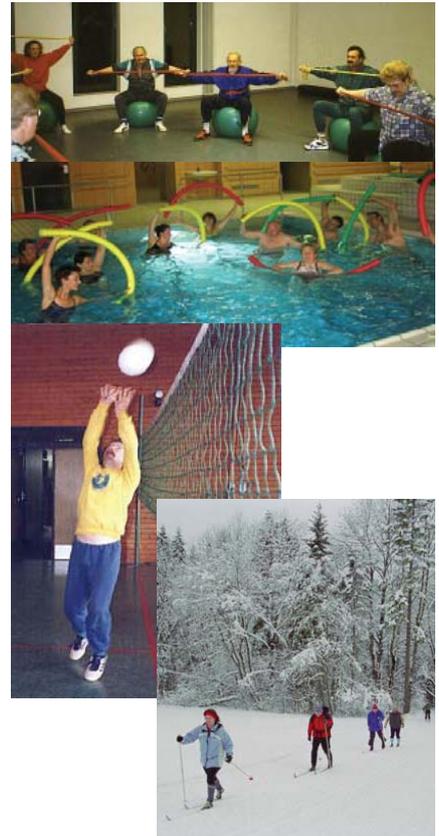
Social support and exchange of experiences

Physicians sometimes fear that meetings of patient organisations may give newcomers a negative idea of their prognosis.

The contrary is, however, the case: Newly diagnosed patients who are dissatisfied with the information received from their diagnosing doctor, often go to a library and find in popular medical books or journals photographs of worst-case patients with severe kyphosis and are shocked and pessimistic about their future career and family life.

Those who get in contact with a patient group, detect that even patients with a long disease duration are often gay and optimistic, take part in common hiking or bicycle tours, play volley ball, and are quite active in their profession.

Many patients have gained by these contacts new ability to cope with life, and it happens that parents join our



Editors Note: Re Common sports - this article was obviously European based and although cross country skiing and nordic walking are both excellent options for AS I feel the travel time may be prohibitive for most.

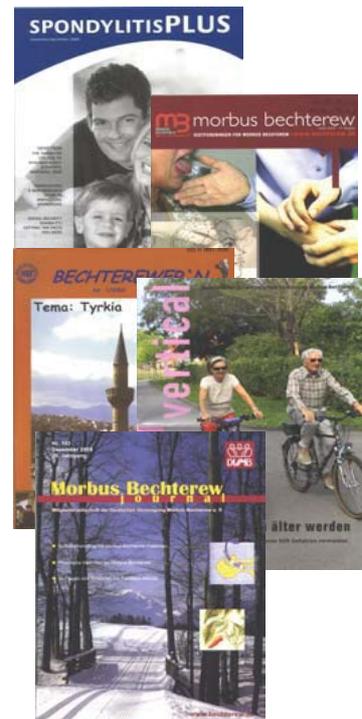


Figure 2: Membership journals of the AS patient organisations in the USA, in Oslo (Norway), in Denmark, in Switzerland and in Germany, as some examples

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Goals of Ankylosing Spondylitis Patient Organisations

Continued from page 3

organisation as sponsoring members, thankful that their son or daughter has found back their humour by these contacts.

Patient organisations thus contribute not only to physical health but also to mental health, a contribution which is an important factor in the way people adjust to living with a chronic disease.

Medical and legal advice

In the office of our organisation in Germany, employees answer about 900 letters and 500 eMails every month, or forward them to experts. answer numerous telephone calls during daytime, and evening telephone hours are offered every month, with an experienced patient or doctor who can answer disease-related questions.

Our medical advisors answer sometimes very unusual questions and often have to investigate medical literature or seek advice from a colleague.

The AS patient organisation was the first patient organisation in Germany employing an own lawyer at their members' disposal.

Seminars for newly diagnosed patients are offered regularly, and also seminars for training the leaders of our local branches.

Membership "prescribed" by doctors



More and more rheumatologists go over to recommend their newly diagnosed patients with ankylosing spondylitis to join the AS patient organisation.

Also the patient education program adopted by the German Association of Rheumatology contains this recommendation.

Nevertheless, only about every seventh diagnosed patient with ankylosing

spondylitis is member of the German AS organisation. The overwhelming majority of patients has either never heard of the great value of joining such a patient organisation, or prefers to try to cope with the disease without any contact to other patients.

Much persuasion is still necessary to make this helpful possibility available for most patients with ankylosing spondylitis.

Disease-specific information

Specific information on the disease including the appropriate everyday behaviour of a patient with AS is essential for the outcome of the disease.

An essential contribution in this respect are

- ▶ Lectures by experts in membership meetings,
- ▶ Membership journals with medical and psychological information, news concerning social laws, book reviews, and experiences of patients on living with the disease (Figure 2).

According to a survey among members of our German AS patient organisation, doctors are the most important source of information in the initial phase of the disease. For current information in the later course of the disease, however, our members regard the society's journal as by far the most important source.

- ▶ Most AS patient organisations provide their members with a "guidebook for patients" containing important hints for living with the disease.

- ▶ The internet web-sites of patient organisations offer information for those who are not yet members, especially for newly diagnosed patients who use the internet as first source of information on the disease.

Representation of patients' interests in society and law

To make our voice heard in the public and in legislation, we are cooperating with other patient organisations.

The objectives of these lobbying activities are

- ▶ a stronger recognition of disability in legislation,
- ▶ improved access to treatments, and
- ▶ the support of research on rheumatic diseases.

The cooperation with other parts of the public health systems also opens additional possibilities of advice and support for our members.

Contribution to research on AS

AS patient organisations represent a helpful pool of patients which may be addressed by researchers.

- ▶ In the 1980s, the Swiss ankylosing spondylitis organisation contributed to research by encouraging their members to participate in a family study under the leadership of professor Sjef van der Linden.

- ▶ Also the British organisation made significant contributions to research in ankylosing spondylitis.

- ▶ In 1996, the German AS patient organisation initiated an extended patients survey with 78 questions answered by 1614 patients with ankylosing spondylitis. The results of this survey appeared in a book and in a number of scientific publications. An especially interesting result of this survey is shown in Figure 3:

Among patients with ankylosing spondylitis diagnosed before 1960, the female percentage was less than 10%.

Continued page 5

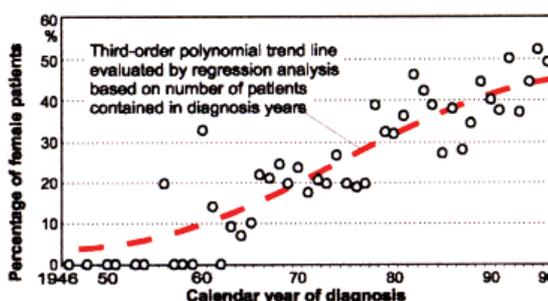


Figure 3: Female percentage among AS patients diagnosed in the years 1946 – 1996. Among AS patients diagnosed recently the female percentage is almost 50%

Goals of Ankylosing Spondylitis Patient Organisations

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The percentage increased continuously in the following decades and is almost 50% among AS patients diagnosed recently.

This means that the 2:1 ratio generally observed in a cohort of AS patients, results from averaging over patients diagnosed recently and patients diagnosed in former decades when female patients with AS were severely under-diagnosed, due to the smaller tendency in females to develop ankylosis.

Please be careful in a lecture on AS: Don't say "males get AS more often than females". The truth is that AS formerly was diagnosed less often in females than in males.

Astonishingly, nobody else besides myself has investigated this dependence on the decade of diagnosis.

Note:- This article has been shortened due to space limitations - Ed

This article appeared in the October 2006 edition of ASIF News - The newsletter of the Ankylosing Spondylitis International Federation.

Back into the Swing of it! Pro Golfer, Ian Woosnam and the challenge of AS

The following article was written by Joan McFadden and appeared in The Scotsman newspaper on 12 July 2005. The follow on article written by Phil Casey also appeared in The Scotsman a year later on the 19th of July 2006 detailing the effects anti-TNF therapy had on Ian Woosnam's Golf....read on

IAN WOOSNAM is no stranger to success. Since his first professional tournament win at the 1982 Swiss Open, the player nicknamed Woosie has become one of the most exciting and best-loved golfers in the world.

In an illustrious career spanning more than two decades, the former world No1 has won the US Masters (1991), finished in the top 12 of the European Order of Merit for 12 successive years, and has been an almost permanent fixture at the Ryder Cup (he will be team captain next year). It is estimated he has won in excess of £3,500,000 in prize money in Europe alone.

As Woosnam makes his 23rd Open appearance at St Andrews this week, he will be an inspiration not only to many aspiring golfers, but to thousands of people suffering from a condition known as ankylosing spondylitis (AS), which affects approximately 1 in 200 men and 1 in 500 women in Britain.

Woosnam was diagnosed with the condition in early 1987, having suffered back pain intermittently for ten years. He was only 29 at the time, which at first glance seems a cruelly young age to be told such devastating news, but is sadly typical of those who develop the disease.

Ankylosing spondylitis is a painful, progressive rheumatic disease, mainly of the spine. It can also affect other joints, tendons and ligaments and other areas, such as the eyes and heart and, while men, women and children can all suffer from AS, it is most common in men, who are nearly three times more likely to develop the condition. It typically strikes people in their late teens and twenties, with the average age being 24.

The cause is not yet known but it has been discovered that almost all the 80,000 clinically diagnosed people in the UK share the same genetic cell marker HLA B27 (human leucocyte antigen B27). There is evidence that a normally quite harmless micro-organism, which would be dealt with by the immune system, sets up an adverse reaction after coming into contact with the B27 individual, triggering the condition and causing flare-ups.

If left untreated, the disease can cause progressive stiffening of the spine, leading to immobility. It is caused by inflammation in the joints between the vertebrae, and of the sacroiliac joints in the pelvis and as a reaction to the inflammation, a small amount of bone erosion occurs. After the inflammation has subsided, new bone is created as part of the healing process and after repeated attacks, this additional bone growth can surround the disc. Effectively this means that the bones begin to fuse together, although most sufferers will only experience partial fusion, usually in the pelvic area.

Sufferers initially experience stiffness and mild back pain, which is worse first thing in the morning but wears off or reduces during the day with exercise and movement. The slow or gradual onset of such symptoms can mean that sufferers do not seek help initially, sometimes until other more worrying symptoms become apparent, such as weight loss, fatigue, fever and night sweats.

But it is important to have this condition diagnosed as soon as possible, since the initial symptoms can be prevented and relieved by regular movement of the areas involved. If this is not done, the formation of new bone can lead to increased stiffness and to deformity with stooping posture in the spine, with the stiffness and deformity eventually becoming irreversible.

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Picture - Getty Images

Back into the Swing of it!

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The best way to stop the progression of AS is to regularly exercise all parts of the spine and the chest area, and if started early and continued regularly - every day - the result is excellent with little restriction of movement or deformity. These exercises are very specialised and have to be done irrespective of the patient's lifestyle. Additional exercises may also be needed for the shoulders and hips, which are the most frequently affected joints other than the spine.

Swimming is a good sport for patients with AS, as it moves the shoulders and hips and anti-inflammatory medication may be prescribed to relieve the pain and inflammation, but it is not a substitute for a regular exercise programme.

The treatment prescribed for Woosnam in 1987 was anti-inflammatories and he then went on to become the first player to win £1 million in prize money in a single year. In so doing, he won eight events around the world, which was a record - the Hong Kong Open, the World Cup individual prize, the Sun City Million Dollar Challenge as well as five victories in Europe.

He was extremely fortunate that he responded well to treatment after AS was diagnosed and has been able to continue his career, which actually helps his condition.

"My doctor said that playing golf was keeping me active and moving," he says. "I do stretching and certain exercises to help the condition and have a personal trainer at tournaments to stretch me before and after rounds."

Woosnam also welcomes the opportunity to help raise public awareness of AS to help people become aware of their condition earlier and get treatment sooner, urging sufferers to be proactive in their treatment.

"You need a good diet and it's important to keep flexible," he says. "Pyshio and swimming will also help and I would encourage people to become aware of any symptoms which would indicate they might have this condition and get treatment as soon as possible."

Until recently the only medication available was non-steroidal anti-inflammatory drugs and many sufferers had to give up work by the time they were in their thirties. Now there are

drugs available which can cause a dramatic difference in the symptoms but many sufferers are not getting them because the cost of around £10,000 a year is considered by health authorities to be prohibitive. The irony is that for just £10,000 many sufferers could return to the workplace, contribute to taxes and society in general and stop putting an unnecessary burden on health and care professionals.

Enbrel, one of the first of the anti-TNF drugs, has been approved in Scotland for use with Psoriatic Arthritis, which is a related condition, but a decision is not due to decide on anti-TNF's for AS until next year. As a result many health authorities are holding off from prescribing it to people who could be helped dramatically. To be diagnosed with AS can be devastating to someone who is young and otherwise fit, but the National Ankylosing Spondylitis Society (NASS) offers the most up-to-date information on treatment and support, and their experience shows that people who take an active interest in their condition can positively influence its outcome.

While Woosnam's tenacity, success and engaging personality position him as one of the foremost ambassadors in world golf today, as he tees off at the Royal and Ancient this week, he will also be a symbol of hope and encouragement for AS sufferers worldwide.

Fast Forward one year....

Injections give Woosie shot at Hamburg victory

Woosnam added a second-round 66 to his opening 65 to lie just one shot off the lead at the halfway stage of the Deutsche Bank Players' Championship in Hamburg.

Sweden's Robert Karlsson leads on 14 under with Woosnam in a share of second alongside first-round leader Lee Westwood (68) and Scotland's Gary Orr (64).

World number five Retief Goosen is a shot further back on 12 under with Ryder Cup team-mates Luke Donald (66) and Pádraig Harrington (65) another stroke adrift on a crowded leaderboard.

Victory tomorrow would be Woosnam's first in a strokeplay event since 1997 and worth £410,000, more than double his previous biggest cheque, for winning the PGA Championship, in a professional career spanning 30 years.

The 48-year-old Welshman was diagnosed with ankylosing spondylitis (inflammation of the spine and the sacroiliac joints) in 1987 and has been taking anti-inflammatories ever since, but revealed a new treatment is working wonders.

"I spoke to Michael King (a former European Tour player) about six weeks ago and after taking these injections he's like a new man," explained Woosnam.

"I saw him playing in the Jersey Seniors Open and he walked all three rounds. In the 18 months before that he couldn't even do 200 yards.

"I decided to take them four weeks ago and it's made a big difference. It's taken a lot of stiffness out of my back and given me the freedom to swing.

"It's called TNF and was developed about 10 years ago for rheumatoid arthritis I think, and then they started using it on ankylosing spondylitis and I've had great success with it.

"It's once a week, a bit like an insulin injection. You just do it yourself and I've seen the benefits already. You can take them as long as you like. There are risks with everything but if I wanted to keep playing to a reasonable standard I needed to do this."

Playing in his 505th European Tour event, Woosnam could become the oldest ever tour winner, succeeding his Ryder Cup vice captain Des Smyth, who was 48 years and 34 days old when he won the Madeira Island Open in 2001. Woosnam will be 48 and 150 days old on Sunday.

(Note: Article has been shortened for relevance to AS rather than Golf for the benefit of AStretch readers - The full article can be found on The Scotsman's online site. <http://thescotsman.scotsman.com/sport.cfm?id=1099212006>)

Footnote: Ian Woosnam shot a 72 final round to finish in a threeway tie for 11th place. His total score was 16 under par.

Physiotherapy - AS Stretches

by Margaret Lewington (B.Phty. Cert Hydro.M.A.P.A)

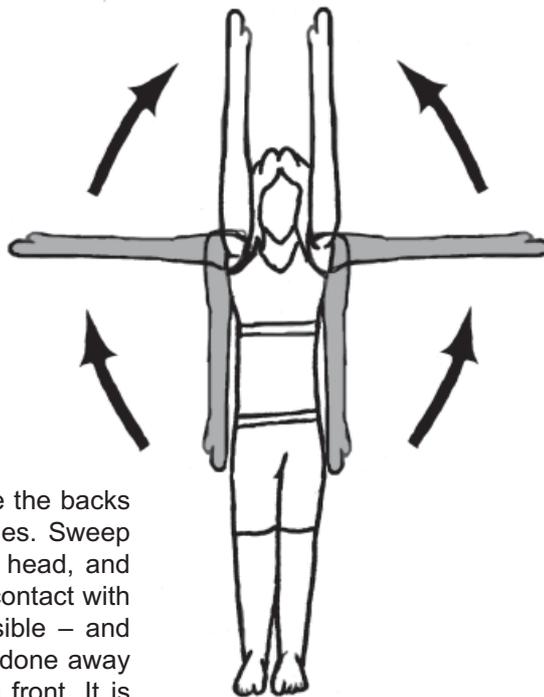
This issue gives a few things to do standing up. If you haven't been doing much exercise recently – these are a few ideas to get you started without having to even get down on the floor!

This may be at home as a regular exercises session, it may be a few things to do as a break while working at a desk or a computer, or perhaps even while out on a walk.

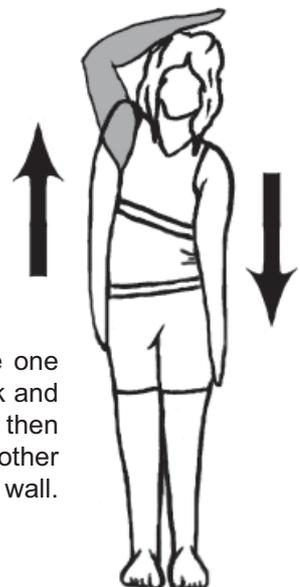
Anywhere – anytime do at least a little.



1. Stand with your back to the wall, as tall and straight as you can, palms facing forward. Drop your chin a little and lengthen the back of your neck. Push back into the wall, or towards it if you are not touching. Relax and let yourself lean forward from the waist – pause – and then stand up straight again.



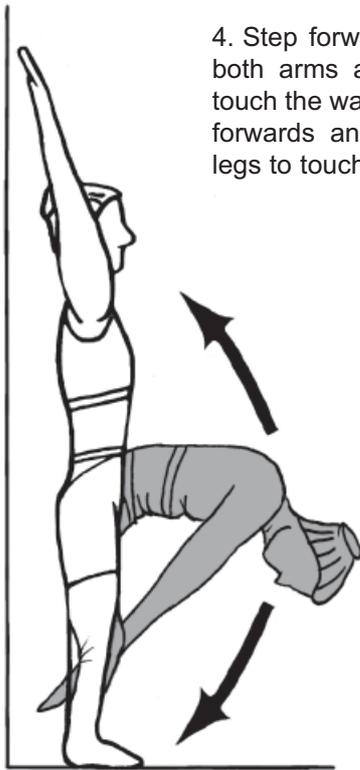
2. Standing with your back to the wall, place the backs of your hands against the wall, by your sides. Sweep your arms up to the sides and above your head, and look up at them. Try to keep your hands in contact with the wall all the way – or as close as possible – and sweep them down again. This may also be done away from a wall, but avoid bringing the arms in front. It is good to check yourself against a wall at times.



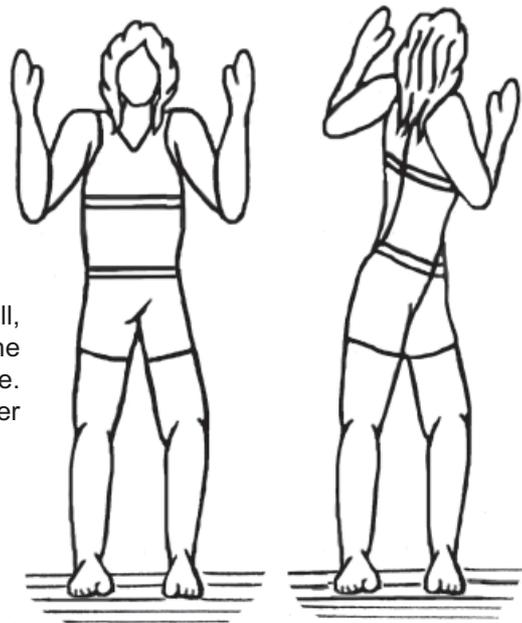
3. Standing with your back against the wall, slide one hand down the side of your leg, keeping your back and both shoulders against the wall. Stand up and then sidebend to the other side. You may also take your other arm up and over your head – on or close to the wall. Keep your feet flat.

Physiotherapy - AS Stretches

by Margaret Lewington (B.Phty. Cert Hydro.M.A.P.A)



4. Step forwards from the wall. Reach up with both arms and lean back over your head to touch the wall, looking at your hands. Now bend forwards and down and reach between your legs to touch the wall - curling your back.



5. Keeping the position a step out from the wall, turn to one side and reach around to touch the wall, at chest height, with both hands if able. Come back to the front and turn to the other side.



6. Walking on the spot. While doing this, do several variations –
 walk briskly and swing your arms fast
 Lift your knees high
 Lift your heels behind
 Walk slowly with large arm and leg movements
 Walk a few steps forward and back
 Try to keep moving for 10 mins

AS Australia Calendar 2006/2007

STATE	EVENT	DATE	TIME	CONTACT
QLD	AS SYMPOSIUM - Deferred to 2007	TBA	TBA	John 3391 4689
QLD	Barbeque at Jack & Joy's	Saturday November 11	From 3.00 pm	Graham 3263 6196
VIC	AS Croup of Victoria Committee meeting at Rosstown Hotel Carnegie Bistro Section - Members Welcome	Tuesday November 21	From 6.00 pm	Belinda Martin 9496 4135
QLD	Christmas Dinner - Venue to be advised	Saturday December 2	7.00 pm	Graham 3263 6196
TAS	BBQ at South Hobart	Thursday December 7	5 - 9 pm	Murray 03 6349 4474
VIC	BBQ at Yarra Bend	Early February	TBA	Belinda Martin 9496 4135
VIC	AS Information Evening Keynote Speaker - Lionel Schachna	Thursday March 1	6.30 pm	Belinda Martin 9496 4135
VIC	Walk at Jells Park for Arthritis week	Early April Weekend	TBA	Belinda Martin 9496 4135

AS Group of Tasmania News

G'day from Tassie, hopefully winter is well and truly over by the time you get this and we can see summer on the horizon. I piked out on the rest of winter after a few too many frosts in June, and July and headed for warmer climes for a few months in early August. I wrote this before heading off so I hope August and September were not too bad for you.

We have organised a Social Function for after we get back and would like to see a few new faces if you can make it.

When - Thursday 7th December 2006
 Time - 5pm to 9pm
 Where - Waterworks Reserve, Waterworks Road, South Hobart. Site 2
 Bring- Chairs, Drinks, Salad to share, something for the BBQ, Plates & Cutlery, Nibbles and anything else you may feel like bringing.

Oh, and positive thoughts for good weather on the day.

Noeli's bit - Well we are certainly grasped in a cold long winter this year and boy do my bones feel it. I told my grandson I had bad bones and the next day he asked me what was wrong with my bones and I told him I had arthritis. From then on he would say "how are your bad bones today Nonna" or "how is your arthurrritis". Well actually it's really bad this year. Back to Bowen treatment for a while. That always seems to help. Murray and Judy have the right idea going off up north for 3 months for some warmth. I've asked if they could fit me in their caravan, I'd even cook and clean but they won't come at it. Never mind! We had a nice winters afternoon at my place the other week and I hope next time I will have a table for everyone to sit round. Keep warm and well. NOELS

Bye for now,
 Murray Limbrick
 Ph 03 6349 4474 or 0400 108874 

"Remember, AS is easier to tackle as a Group."

- AS Group of Tasmania

SPRING 2006

AS Group of Queensland News by John Ebert

On behalf of your committee, I apologize that we had to defer our Symposium on Saturday 2 October due to circumstances beyond our control. We are planning to hold it next year and are already planning our presenters to make it even bigger and better than this year's would have been. Look for details in forthcoming editions of AStretch.

Our September dinner at Michael's Oriental Restaurant at Eight Miles Plains, was voted a great success by the dozen people who attended. Each course of the banquet was delicious and well presented. The regular dinner attendees were pleased to welcome Melissa and James to their first AS dinner. We look forward to seeing them at many more functions.

In August, at the invitation of Professor Matthew Brown, I was pleased to attend the Symposium on Arthritis held for the second year medical students at Royal Brisbane and Women's Hospital. I was, of course, the AS patient who spoke of how the condition affects my life and how I manage to live with the symptoms. Professor Brown then spoke about AS and asked me some questions to further demonstrate how patients can manage their condition. I thank Professor Brown, not only for this opportunity to spread the word about AS and the AS Group of Qld, but also for his continuing support of the group and providing us with his excellent and informative articles for AStretch.

As some of you are aware, the group is in the post production stage of a DVD of land exercises for people living with AS. On the last weekend of July, Margaret and I attended a Rheumatology Conference sponsored by Schering Plough at Sanctuary Cove where the DVD was launched to the Rheumatologists who attended. Final production has been held in abeyance whilst we are still working on the art work for the cover. I am pleased to be able to announce that a copy of the DVD will be given to all current financial members and to those who either rejoin or join the group in the future. I acknowledge the generous financial support from Schering Plough in financing the production of this DVD.

This reminds me to mention that annual subscription was due on 1 July this year. If you are in doubt as to whether your subscription is currently up to date, please do not hesitate to contact me either by phone on 33914689 or via e-mail queensland@asaustralia.org.

It is also the time of year when subscriptions to our parent body, Arthritis Queensland, are due. I encourage all members of the AS Group of Qld to either renew their membership to or join Arthritis Queensland. They can be contacted at PO Box 2121, Windsor, Qld 4030, tel 38574200 or email info@arthritis.org.au.

Congratulations to Adrian and Helen Bloomfield on the birth of their second daughter, Camille Maeve, who was born on 9 July weighing 2.685 kgs. Camille is according to a proud and smitten dad "a darling baby. Quiet and placid." However, big sister, Morgan, more than makes up for it. I look forward to meeting Camille at one of our dinners and know how well she will be loved and nurtured by all in her family.

I extend the group's condolences to long time member Beverley Mansfield and her family on the recent death from cancer of her husband John. May he rest in peace. 🕊



I thank Professor Brown, not only for this opportunity to spread the word about AS and the AS Group of Qld, but also for his continuing support of the group and providing us with his excellent and informative articles for AStretch.

HYDROTHERAPY

Pool Exercise Sessions
for people with AS

Supervised by Margaret Lewington
(B.Phty. Cert Hydro. M.A.P.A.)

WHEN: Tuesday Nights
TIME: 6.30 – 7.30 pm

WHERE: Hydrotherapy Pool,
Level 2, Ned Hanlon Building,
Royal Brisbane & Women's Hospital,
Butterfield Street Herston.

COST: \$8 or 10 classes for \$75

ENQUIRIES:

Margaret (07) 3376 6889 or
John (07) 3391 4689

Hydro News by Margaret Lewington

Over the last 10 weeks, we have been fortunate to have the help of four 3rd year physiotherapy students at our weekly hydro class sessions. They have been doing their 'Health and Wellbeing' Placement, and I have taken this opportunity to have available both the usual 1 hour pool session as well as a choice to do 45 minutes gym exercise followed by 45 minutes pool session.

There has been an enthusiastic response to this, with at least 15 people choosing the double session. Many positive comments have been made along the way, as well as comments that some have found it challenging and feeling stretched in new and different places. It has encouraged some to do more exercise at home, giving them a

few new ideas of what to do and the encouragement to give it a go. We are currently evaluating a questionnaire to assess the response and interest. We would like to offer this more often, but previously space, time, staff and interest has made it difficult. Maybe we can overcome some of these now.

We are grateful to the students for getting involved and helping us have this opportunity. Also to the medical student who joined in enthusiastically. They are also grateful to us for providing them with the opportunity to learn more about AS and about groups in the community, and thank everyone for being willing to give it a go. Thankyou to all - Marg.

AS Group of Victoria News

President's Report:

The office bearer's have been re-elected for the 2006/07 year.

The positions are as follows:

President: Annie McPherson.

Treasurer: Rosemary Stephens.

Secretary: James McCracken.

ASstretch Editor: Greg Tate.

We have received and processed another 7 membership applications taking our total membership to over 55 members. Membership renewal forms have been recently distributed. We have also requested members to indicate if they are members of Arthritis Victoria to avoid double up of information.

We would like to see more personal stories for the Newsletter and would also like to hear about your TNF blocker experiences to enable a patient based overview of this new treatment to be presented. These stories always generate great interest. If you have something to contribute, you can contact the AStretch editor via email. ASstretch@swiftdsl.com.au

The AS Group of Victoria Christmas in July dinner, was held on Friday 23rd July, 2006 at the Rosstown Hotel, Carnegie. It was well attended by the working committee and several new members. We all agreed this was a good venue and we would repeat the event next year. Some members had to depart early to retrieve family members from The MCG and some had travelled from Mornington so the evening finished well on time. Thanks to all for the invitations, mail out and organising the hotel.

On July 27, 2006 Dr Lionel Schachna (Austin Spondylitis clinic) introduced Professor Jurgen Braun, a specialist in AS visiting from Germany to an Austin medico's workshop. The workshop focused around a hypothetical patient displaying characteristics of AS. The health professionals were encouraged to discuss the various measurements and scales used in the diagnosis of AS. Professor Braun contributed comments of some aspects of measurement and scales in present day use and their relevance. At present an early diagnosis patient criteria is being considered (in Europe) for a study paper.

Annie recently met with John Ebert of the AS group of Queensland in Brisbane to discuss progress of various projects as outlined below:

Western Australia ARA / RHPA: Rheumatology seminar was attended by Margaret Lewington (physiotherapist) and John Ebert. Both participants were invited to speak on the AS Group and hydrotherapy. An information flyer targeted at the health professionals informing them of the AS Australia Groups was distributed. Margaret and John were also able to meet with the AS Group of Perth and it is great to welcome them to our association.

National AS Australia Group: John and the AS Queensland committee have been making excellent progress towards a united AS Group for Australia. At present we have suggested Belinda Martin (Austin Spondylitis Clinic) would be our best contact person for Victoria for the website.

Schering Plough has been sponsoring the production of a DVD on land exercise for AS patients in conjunction with AS Queensland. This DVD will be made available to AS Victoria members.

A Hydrotherapy DVD is still in production and should be available later in the year. This will be promoted and distributed by the AS Group of Qld.

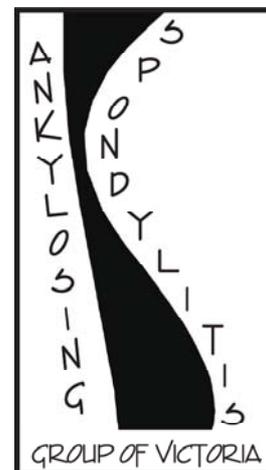
I also attended a hydrotherapy class at the Royal Brisbane & Women's Hospital in Brisbane. The class is conducted by Margaret Lewington in a deep hydrotherapy pool. The evening was attended by approximately 15 AS patients with a very vigorous exercise program.

Belinda Bradbury of the Ankylosing Spondylitis specialist clinic at the Princess Alexandria Hospital attended the hydrotherapy venue to catch up with patients participating in their research program.

John also reported the NSW Group has become inactive. There have been suggestions that the NSW and Tasmanian groups might be serviced best, from an information dissemination basis, by merging into the Qld and Victorian groups to keep their members up to date. I will discuss this further with interstate representatives.

Back on the Victorian front, The AS Group of Victoria Support Group Meeting was held on Tuesday, 3rd October, 2006 at Ivanhoe Receptions, Ivanhoe. This informal group discussion evening was an excellent opportunity for members to chat to other people with AS about dealing with Ankylosing Spondylitis. Presentations were made by various committee members on the latest happenings on the AS front in Victoria, including details on an upcoming Hydrotherapy course at Caulfield Community Hospital and an outline on the following AS Group of Victoria activities for 2007.

AS Self Management course
Hydro Gymnasium/Land exercise
Group support meetings
Seminar with Arthritis Victoria
BBQ at Yarra Bend Park
Picnic / Walk at Jell's Park 



AS Group of Western Australia News

The WA group holds two sessions of land exercises and hydrotherapy each Monday at the Shenton Park Hospital. While one group of participants starts with hydrotherapy, another commences with land exercises and after an hour they swap. It is an excellent way to achieve a balance between land and water exercises.

Western Australia Hydrotherapy (Perth)

Where: Royal Perth Rehabilitation Hospital
Shenton park Annexe Selby St Shenton Park.
When: Every Monday evening (Public Holidays excepted)
Cost: \$6.00
Times: Hydrotherapy Pool
5.30pm - Hydrotherapy exercises
Gymnasium
5.45pm - Land exercises

All sessions are conducted by experienced Physiotherapists.
Total session time is two hours with groups changing over at end of first hour.

Coping Strategies by John Ebert

As the first contact person for the AS Group of Qld I am often confronted with people who are recently diagnosed with AS, some who were diagnosed for longer periods, sometimes years, who have done nothing about their AS and various family members and carers. The one question I am regularly asked is "How do we cope". From my personal experience and talking with many people who successfully live with AS, I suggest that there are points for successfully living with AS. These are:

1. Accepting the reality of the diagnosis of Ankylosing Spondylitis and accepting that it is not a "death sentence". This often occurs after a grieving period, similar to the death of a loved one and a period of learning about the condition.

The one question I am regularly asked is "How do we cope".

2. Refusing to have a present and future which is hopeless.

3. Willingness to make adjustment to their lifestyles and how they see their and their loved ones futures. Many people bring forward future plans to enable them to obtain fulfillment of their dreams.

4. Active participation in partnership with their health professionals and taking responsibility for their own health, often becoming the leaders of their health team and willingly making informed choices to benefit themselves.

5. A powerful belief that life is always worth living to the full.

6. A belief that they are supported by peer support groups and as members can offer support to others. I often hear from people the empowerment that they feel from meeting and speaking with others living with AS and how this is a life changing experience for them.

7. Finding specifically designed exercises that have great benefit to help them cope with their daily lives. (I feel a deep gratitude to one of my heroes, Jane Barefoot, for developing so many of the exercises that help me every day).

8. Finding value in these exercises and general fitness and a willingness to share these benefits with others.

9. Developing a non-selfish nature that is concerned about self care and a willingness to say "no" when it may benefit themselves, their partners, families or carers in a positive way.

10. An ability to listen to their bodies and the messages they receive.

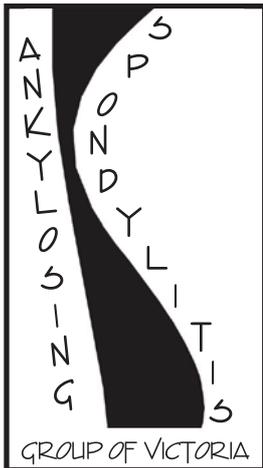
11. An ability to be good communicators about how they feel, their needs, fears, desires and great abilities to live the lives they desire.

I am humbled by the willingness of people to share their stories, abilities and desires with me and I thank each and everyone who has shared their life stories with me. I look forward to a wonderful future for us all and hope that these pointers may help others to lead a more fulfilling life living with AS. 

PS. I recently attended a kite exhibition held in Coolool and was most taken with the following (AS) kite created by kite master Wen-Fu-Tsai, proving that Penguins really can Fly!



AS Group Membership Form



Ankylosing Spondylitis Group of Victoria Membership Application Form

I wish to become a member of the Ankylosing Spondylitis Group of Victoria and enclose my remittance, contact details and preferred membership type.



YOUR CONTACT DETAILS:

Name:

Address:

Telephone:

Email:

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



MEMBERSHIP TYPE:

Note: Membership runs through to 30th June 2007

- | | | |
|--------------------------|---|---------|
| <input type="checkbox"/> | Full: (Includes mail out of Newsletter) | \$25.00 |
| <input type="checkbox"/> | E-mail: (Newsletter by e-mail only) | \$20.00 |
| <input type="checkbox"/> | Concession: * | \$20.00 |
| <input type="checkbox"/> | E-mail Concession: * | \$15.00 |
| <input type="checkbox"/> | Donation: | \$ |

TOTAL:

\$

*Please make
cheques or money orders
payable to:

Ankylosing Spondylitis
Group of Victoria*

* Concession rate available for pensioners, unemployed with health benefit card & full time students with student card



RETURN COMPLETED FORM TO:

Ankylosing Spondylitis Group of Victoria
P.O. Box 3166
Burnley North, VIC, 3121.



FOR MORE INFORMATION:

Contact Belinda Martin - (Phone) 03 9496 4135 (Email) belinda.martin@austin.org.au