ASTRETCH

SPRING 2020 **www.asaustralia.org**

ANKYLOSING SPONDYLITIS AUSTRALIA

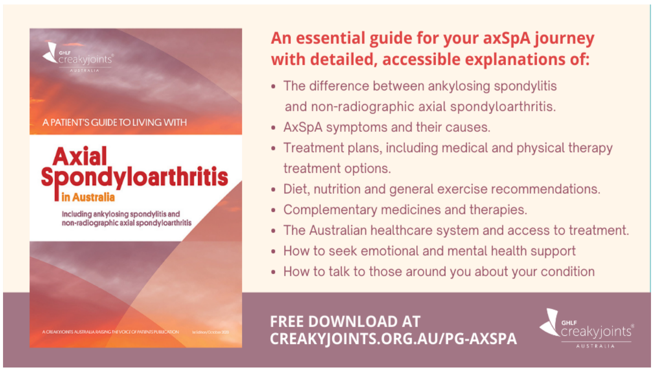
A Patient's Guide to Living with axSpA *by Rosemary Ainley*

CreakyJoints Australia's **exciting new handbook for Australians** with autoimmune spinal arthritis

Have you ever wished that you had a guidebook to help you through every step of your journey with axial spondyloarthritis (which includes ankylosing spondylitis and non-radiographic axial spondyloarthritis)? While there is a lot of information about "what" the conditions and treatments in this area are, there hasn't been a comprehensive guide about "how" to deal with them. Until now.

CreakyJoints Australia (CJA) has just launched: "***A Patient's Guide to Living with Axial Spondyloarthritis in Australia***" which is now available as a free download from our website:

creakyjoints.org.au/pg-axspa.



An essential guide for your axSpA journey with detailed, accessible explanations of:

- The difference between ankylosing spondylitis and non-radiographic axial spondyloarthritis.
- AxSpA symptoms and their causes.
- Treatment plans, including medical and physical therapy treatment options.
- Diet, nutrition and general exercise recommendations.
- Complementary medicines and therapies.
- The Australian healthcare system and access to treatment.
- How to seek emotional and mental health support
- How to talk to those around you about your condition

FREE DOWNLOAD AT CREAKYJOINTS.ORG.AU/PG-AXSPA

The CJA team all live with arthritis and we know that our healthcare providers can't answer all our important questions, such as "How do I deal with my diagnosis?", "What supports are available to me?" or "Are medications my only treatment option?". That's where this guide fits in.

This practical guide for living with axial spondyloarthritis (axSpA) has been set up for you to dive in and get the answers you need when you need them. Even better, we've written it in everyday language and have checked all the information with esteemed rheumatologist Professor Paul Bird from Sydney.

Feel free to share the link to this guide with anyone you think will benefit from it, including your healthcare team. You are also welcome to send your feedback to info@creakyjoints.org.au

Check out the CreakyJoints Australia website (creakyjoints.org.au) for more tips and resources for living well with arthritis.

CJA would like to thank the amazing Annie McPherson for giving her time to extensively review a draft of these patient guidelines and to Craig White and Shayne van der Heide (also from Ankylosing Spondylitis Victoria) for supplying comments about their own experiences with axSpA.

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Recent Research Papers on Disease Progression

reviewed by Margaret Lewington

Tumour Necrosis Factor inhibitors slow radiographic progression in patients with Ankylosing Spondylitis: 18 year real world evidence.

Bon San Koo, et al. Ann. Rheum Dis. 2020 South Korea

ABSTRACT:

Objectives: Tumour Necrosis Factor Inhibitors (TNFis) have been suggested to slow radiographic progression in patients with Ankylosing Spondylitis. However, limitations such as variation in disease activity, complex drug administration and short follow-up duration make it difficult to determine the effect of TNFis on radiographic progression. The aim of the study was to investigate whether long term treatment with TNFis can reduce radiographic progression in patients with Ankylosing Spondylitis using 18 year longitudinal real world data.

Methods: This retrospective study was conducted between January 2001 and December 2018 at a single centre. Among the 1280 patients whose electronic medical records were reviewed, data of 595 patients exposed to TNFis at least once were included. Among them, time intervals of TNFi exposure or non-exposure were determined in 338 patients ('on the TNFis' or 'off the TNFis' intervals respectively). The difference in the modified Stoke Ankylosing Spondylitis Score (mSASSS) change rate between 'on the TNFis' and 'off the TNFis' was investigated.

Results: We obtained 2364 intervals of 338 patients (1282 'on the TNFis' and 1083 'off the TNFis' intervals). In the marginal structural model for inverse probability of treatment weighting, the change rate of mSASSS significantly decreased with the use of TNFis (B= -0.112, p= 0.004), and the adjusted mSASSS changes were 0.848 and 0.960 per year during 'on the TNFis' and 'off the TNFis' intervals, respectively.

Conclusion: Compared with treatment without TNFis, treatment with TNFis slowed radiologic progression significantly.

Extracts from the article:

Radiographic damage in AS is commonly manifested by erosions and sclerosis beginning early in the corner of vertebra, eventually leading to syndesmophytes and ankyloses. mSASSS is most commonly used to assess radiographic damage. Factors affecting radiographic progression are younger age, male sex, HLAB27 +, shorter symptom duration, long disease duration, high disease activity and smoking. TNFis dramatically improved symptoms by blocking TNF cytokine that plays an important role in inflammation. Although some previous studies showed that they may not have an effect in reducing radiographic progression, several accumulated data on the efficacy of TNFis suggest that TNFis may affect radiographic progression in patients with AS.

A complex statistical analysis was used to compare between drug intervals on the same patients, not between patient groups, and revealed that the rate of progression while 'on TNFi' was far less (0.848) compared to when patients were 'off TNFi' (0.970).

Limitations of the study include not including smoking status, not including patients who have never taken TNFis, and that they imputed the mSASSS data with interpolation, because the mSASSS tends to increase very slowly with radio-

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logic progression in the real world. However, the imputed values, such as those for inflammatory markers or disease activity, may differ from the actual values owing to the large variability during the observation period.

Changes in mSASSS were significantly associated with age at diagnosis, the presence of HLA B27, eye involvement, female sex, inflammation at the start of the interval and the use of DMARDS and TNFi. Treatment using TNFis is among the modifiable factors for radiographic progression in patients with AS.

Comment: Radiographic progression seems to develop in the presence of persistent inflammation, however, the exact mechanism is still not clear. Hence, if we reduce the inflammation, disease progression should be reduced. NSAIDS have been shown to retard progression, Biologics are very successful at reducing inflammation, and hence no doubt also retard progression. This study, using complex statistics, showed some decrease, (0.848 points per year vs 0.960 points per year) but not stopping progression. Also, if inflammation is low, regardless of medication, progression should also be low.

No Radiographic sacroiliitis progression was observed in patients with early spondyloarthritis at 6 years: results of the Esperanza multicentre prospective cohort.

Fernandez-Carballido, C et al.
RMD Open 2020 Spain

ABSTRACT

Objective: To estimate the six year radiographic progression of sacroiliitis in patients with early Spondyloarthritis (SpA).

Patients and Methods: Sacroiliac joint (SIJ) radiographs (baseline and six years) of 94 patients with recent-onset SpA from the Esperanzo cohort were scored, blindly and in a random order, by 9 readers. The modified New York criteria were used to define the presence of sacroiliitis. As the gold standard for radiographic (r) sacroiliitis, the categorical opinion of at least five readers was used. Progression was defined as the shift from non-radiographic (nr) to r-sacroiliitis.

Results: In the 94 SIJ radiographs (baseline and six years), 78/94 (83%) pairs of radiographs had not changed from baseline in six years. Sacroiliitis was present in 20 patients at baseline (21.3%) and in 18 (19.2%) patients at six years; 11 patients had sacroiliitis at both the baseline and final visits; 9 patients changed from baseline r-sacroiliitis to nr-sacroiliitis at six years, and 7 changed from baseline nr-sacroiliitis to r-sacroiliitis at 6 years. The reliability of the readers was fair and mean agreement was 73.7%

Conclusion: In the early SpA Esperanzo cohort, progression from nr-axSpA to r-axSpA over six years was not observed, although the SIJ radiographs scoring has limitations to detect low level of radiographic progression.

Discussion: Longitudinal studies about the change from nr-axSpA to r-axSpA have shown rates of 10 to 12% progression over 2 years and a recent review disclosed a progression rate of 10 – 40% over a period of 2 to 10 years. We have shown a small but negative 'net' progression that, given the early nature of the cohort (patients with a disease duration of less than 2 years), would suggest no progression. The reported 'net' progression in the DESIR and ASAS cohorts was 5.1% at five years and 5% at 4.4 years of follow-up, respectively. At first glance, it would seem that recent studies are detecting less SIJ radiographic progression than the classical ones.

This study, with a high predominance of nr-axSpA (78%) could result in lower global rates of progression, but another study has shown that patients with nr-axSpA showed even more progression (10.5%) than those with AS (4.4%). A German study showed patients with nr-axSpA and AS not treated with TNF blockers demonstrated a similar clinical disease course over 2 years.

A proportion of patient with nr-axSpA might never develop definite radiographic damage, whereas others will experience a shift from nr-axSpA to r-axSpA.

In Summary, in this group of patients with early SpA, no progression from nr-axSpA to r-axSpA over six years was observed. The limitations in the rating of the SIJ radiographic might impede the detection of low levels of radiographic progression, especially in early cohorts of axSpA.

#DontWaitMate by Dee Lynch

Don't Wait Mate is the campaign developed by the newly created Continuity of Care Collaboration (CCC) to encourage Australians to continue to monitor their health and attend regular screening and appointments during COVID-19 restrictions. The CCC found that 52% of Australians were not attending to their health care due to COVID-19 which is not only detrimental to the long-term health of Australians, but they were not getting immediate assistance or following up new symptoms.

The CCC includes a variety of organisations including the Heart Foundation, Carers Australian, Epilepsy Action Australia, Prostrate Cancer Foundation of Australian, Pharmacy Guild of Australian and Mental Health Australia, all encouraging patients and their carers that it is safe to attend medical appointments and tests. For most patients, appointments may look a little differently due to Telehealth, e-prescribing of medications, medications being delivered to your home and everyone involved wearing personal protective equipment with regular cleaning and social distancing. All these measures are to project you as the patient and the health care provider leaving no reason for you not to continue your regular health care treatment and checking in with your healthcare professional.

The www.continuityofcare.org website provides links to recent webinars on accessing healthcare and how to get involved with this campaign. While there is no budget for the campaign, the CCC relies on health organisations and individuals to use the #dontwaitmate on social media and publications such as this one. So get the message out there #DontWaitMate!

Continuity of Care Collaboration:

Over the past couple of months the CCC and the Consumer Health Forum (CHF) have been providing various Healthcare webinars produced by a range of Aust. Patient support networks and communities.

A number of our teams, have been participating and here is a brief summary of some of the webinars available on their website:

Consumer Health Forum:

 # Digital Health The speakers presenting this webinar talked about the recent changes to our healthcare system including Telehealth and video consultations, and e-prescribing. These changes have been accelerated by the Aust. Government Health Department in our Healthcare system in response to the coronavirus pandemic.

 # Partnership to Better Health - social prescribing. The speakers in this webinar addressed the need for patients to work with their Healthcare and Social Services team to ensure they manage all aspects of their Healthcare including mental health, exercise programs, and welfare programs.

 # Preventative Health - this webinar's speakers covered the need for patients to continue with their Healthcare scans, tests and treatments which may initially have been delayed by the Healthcare system's response to the coronavirus pandemic.

Links:

Continuity Of Care: Webinars

The webinar transcripts may be viewed from the CCC website and are well-worth listening too.

Dee Lynch

Loss, Grief, and Living with Chronic Illness *by Jen Hall*

Some of you may have read my previous article in AStretch (*2019 Winter edition)* about how to introduce simple daily changes to create cumulative healthy habits in coping with AS. This article speaks to the emotional experience of living with chronic illness.

Previously I shared that as well as working as a counsellor and psychotherapist, I also have a couple of autoimmune diagnoses myself, including AS. I would also add that I have been a carer for both my 84 year old parents for the last 14 years: one of whom has had chronic physical and mental health issues for many years, and the other parent now with chronic health issues. So I write these articles with some understanding of what it's like to live with chronic illness from patient and carer perspective. Each person's experience is unique, and changes can occur quickly and fluctuate, with our state of health and well-being.

There is an aspect of loss in chronic illness that often unintentionally is unacknowledged by the patient and other people associated with a patient: family carers, friends, medical care team, employers and colleagues etc. I'm referring to the associated emotional experience of grief. Loss and grief can sometimes be pushed aside, becoming disenfranchised. This can include perceived future loss which can cause anticipatory grief. Loss and grief are very personal experiences, unique to each person's circumstance and perception. This article aims to raise the reader's awareness of loss and associated disenfranchised and anticipatory grief as they relate to living with chronic illness.

A short definition…

Disenfranchised grief is where a loss and the felt emotional disturbance is not acknowledged or is dismissed by the community for any number of reasons: or the emotional disturbance is not acknowledged or is dismissed by self by soldiering on or getting stuck in unexplained "depression". This is not a criticism of soldiering on, which, when done with full awareness and acceptance, can be beneficial. More about that later.

Anticipatory grief is where we anticipate a loss and live with emotional impact of the known or unknown factors about future. In this context we are talking about health and the broad impact on life. As we try to navigate thoughts about the future there can be a strong emotional disturbance triggered by loss experienced as anxiety. Humans naturally are concerned about the future which can be a driving force to create security and well-being: in normal circumstances it's a drive for survival that we all possess.

There are many excellent psychology theories on grief. The most appropriate theory that describes the uniqueness of a person's experience of grief was by John Bowlby the originator of Attachment Theory. Without going into depth, in broad terms, the pearl that applies to loss and grief is that our sense of loss, and the associated depth of emotional experience are determined by the magnitude of attachment to that we perceive we have lost. This can also include anticipated loss. We are naturally attached to living a long healthy life.

My personal experience and professional observation of long term chronic illness highlights to me the loss and grief aspect of living with chronic illness. What stands out to me in all cases is the disenfranchised grief that is prevalent in chronic illness and can often be sidelined and when acknowledged is treated as broad depression: rather than treating the grief process with care and attention. I am not dismissing depression as a diagnosis, simply providing an alternative way of looking at it.

Equally challenging and often unacknowledged is the anticipatory grief and the corresponding anxiety that goes hand in hand with an unknown future, and also knowing that a future previously dreamed of could have to be changed quite drastically due to the health condition we are trying to navigate. These forms of grief also apply to carers and family members who are going along the journey with you, for better or for worse.

It's important to acknowledge that a person living with a chronic illness is reminded on a moment by moment basis of current loss in physical terms. This can be through experiencing symptoms of pain, fatigue, mobility issues etc. As we go about our daily business in whatever capacity possible there are regular and often unpleasant reminders of how our bodies have changed, and are continuing to change.

I hope to raise awareness in this article of these two types of complicated grief in the hope it will help AS patients and their families/carers understand the emotional impact. Understanding emotions, being able to name feelings and experiences can often go a long way towards alleviating emotional stress, and even point you in a direction of an improved mental/emotional experience where possible, and knowing when to access support.

When there are obstacles to our survival our body's nervous system prepares us to fight, flee, or freeze as part of a natural survival mechanism. In terms of historical context we would fight or run like crazy from the Sabre Tooth Tiger, a real and present danger.

Loss, Grief, and Living with Chronic Illness *continued from Page 5*

Freezing was never a good option with a tiger on your tail. When that danger was resolved we could then recover and our nervous system would engage in the rest and digest process. The move from one survival mechanism to another ensured a balance of a break from stress to allow our bodies to recover and regenerate.

In the previous article I mentioned research on the impact of chronic daily stressors. I'm sure you are connecting the dots here and realised that there can be a continuous arousal of our "fight, flight, freeze" system: triggered by ongoing physical symptoms; pursuing care and solutions; and worry about the present and future of our health. This continual stress response creates a loss of recover and regenerate in our emotional experience. However we can work with this in positive ways.

To start the awareness process I'll list some perceived loss that could cause a grief response: not exhaustive by any means. A loss is a personal experience that relates to what you value.

Physical/health loss: agility, mobility, comfort (pain and stiffness), height, dealing with side effects of medication, appearance, sight, feeling well, wakefulness and energy, youthfulness…

Other forms of loss: favourite activities, keeping up with a partner or children, shared activities, sport, friendships may drift apart, employment, career, finances, autonomy, ability to drive, sense of control, dreams of the future being a certain way, memories of what was, current and future security…

This is all really important stuff in anyone's life. You might notice that a family carer and other family members would experience many of the types of losses mentioned.

Unlike losing a loved one who has passed away, losses of a different nature can easily go unacknowledged, misunderstood, and even frowned upon by someone who is not having the same experience. This is where a patient's emotional experience of chronic illness becomes Disenfranchised Grief: the emotional suffering can be internally amplified, or quashed to appear in another emotional form such as depression, anxiety, and sometimes anger. The same disenfranchisement can happen to a patient's experience of Anticipatory Grief which is understandably expressed as anxiety about the future in very real terms: all valid.

The same applies to carers and family who feel intense loss in their own circumstances. Their loss is often disenfranchised and anticipatory as well, from whatever their experience is: also all valid.

So in an experience of chronic illness there are distinct and shared experiences of disenfranchised and anticipatory grief that, if brought to personal awareness, may be worked through and healed to some extent. The patient and carer would be encouraged to look deeply into their own perceived losses, acknowledging, accepting and bringing self-understanding. Along with this process it is also important for the patient and carer to appreciate and understand the other's experience. Awareness, acceptance of reality, and an attitude of compassion is the starting point to potentially having a healthier mental and emotional experience of living with chronic illness. The situation or grief is not going to magically disappear. It's our job to find healthy ways (healthy daily habits) to work through the process of life as it is. That is the most likely way for positive emotional change to occur.

There are many strategies for working with our grief. Let's see if for sake of brevity we can put some ideas into 4 tasks (William Worden's) that are often applied more globally to grief experiences.

The first task: Accepting the reality of the loss - Acknowledge what your own perceived losses are. They are real and tangible to you including the non-physical and symbolic losses. Acknowledge and accept the reality of what you feel you have lost, or may lose, with deep care and compassion. Tears are OK. It's natural to feel angry, disappointed, and even scared.

Second task: Working through pain and grief. This means physical, mental, and emotional. Work through the emotional experience by acknowledging the depth of feelings you have, and at the same time work with your care team to do all you can to care for your physical and emotional needs in healthy ways. This goes for carers too. Self-care is critical. Being proactive within any limitations can give you a sense of power, autonomy, and ability to manage your life.

Third task: Adjusting to the new environment - Adjust and adapt to your current physical capacity and circumstances. Remember the "incorporating new daily habits, one step at a time" article (available on my website). This includes finding new ways to do the things you love as well as the things you need to do. If you absolutely cannot do things you used to do, then it's time to get creative and find some new interests within your capacity.

Fourth task: Finding a connection with what is lost and moving on with life - In chronic illness I see this as evolving all three previous tasks into a new way of functioning day to day. Do more of adapting so that you can find new ways

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to physically and emotionally be with what is lost. Park the past in the past, love it for “then” and be with “now”. I’m sure you have made some wonderful memories to treasure. Visit the memories with joy and then concentrate on making new treasured memories here and now. Focus more on what you can do rather than what you can’t. Remember you have already acknowledged the past (in task 1) by accepting what you feel has been lost. If you are breathing, there is a future, and you will naturally plan as much as you can. The key is to keep returning to the present, address what you need to, and then focus on what you want to.

Look at the amazing role models of Christopher Reeves and Stephen Hawking. You don’t have to be a Hollywood actor to achieve these tasks. In fact Christopher Reeves acting career was over after his riding accident. He had to completely adapt his world - physically, emotionally, relationally to survive and experience satisfaction. He succeeded in doing that: his wife also had to make massive adjustments in finding new ways to be married to a man on life support.

Stephen Hawking found new ways to continue doing what he loved. His life was a great example of adapting to progressing chronic illness. Can you imagine the loss and grief both Reeves and Hawking had to accept and process to continue on to lead lives that felt meaningful to them?

This article’s aim is to guide people to identify and acknowledge the challenges faced through anyone’s level of disability, pain, or experience of all stages of chronic illness. Grief in chronic health diagnosis can be debilitating to someone who you might not even recognise as physically ill. If you are the patient I encourage you to not compare experiences with someone who is obviously in a different stage of illness. Simply acknowledge and work with your own physical and emotional reality to help you move through the challenges with some sense of peace and grace. Carers need to also acknowledge their own experience. Imagine the shared healing process if patients and carers could experience shared compassion. What healing doors could be opened?

Link to previous article: http://kissprinciple.com.au/healthy-daily-habits-are-anti-inflammatory/

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Rationing the spoons

by Dee Lynch

When you are battling a chronic condition like Ankylosing Spondylitis and dealing with ongoing pain and fatigue, there is a real need to constantly plan ahead to ensure you have enough energy to get through the day. Everyday tasks all require extra planning and extra energy and without planning ahead, you could be recovering for days afterwards and bring on a flare.

This is where “The Spoon Theory” comes in to easily explain how a chronic illness can separate what you would like to do each day compared to what your body is allowing you to do.

The Spoon Theory was developed by Christine Miserandio in 2003 to visually explain to friends how she managed dealing with lupus and using up mental and physical energy. Christine explained if she started the day with 12 spoons, every time she completed a daily task a spoon was taken away, for example a shower (1 spoon), washing hair (1 spoon), reaching up high (1 spoon) when 6 spoons had been removed before she had even started the day! After work there may be 1 spoon left to either eat dinner, clean up dishes or do something fun, there is no choice to do them all.

It is possible to use up your daily quota and then “borrow” from the future however there is then the risk of running out that day too. Often those with chronic conditions such as Ankylosing Spondylitis have sleep difficulties which can mean the day starts off with less spoons than planned.

It is possible to plan ahead and “save up” spoons for a special occasion such as catching up with friends or going to the movies. With fulltime work and caring for a beautiful teenager, I have always used up my spoons by the weekend. I find having an afternoon nap, online shopping and asking the family to help clean the house means I have enough spoons to go out for a meal with friends.

How do you manage your “spoons”?

Dee Lynch

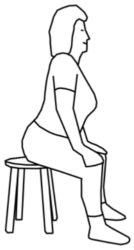
The Spoon Theory by Christine Miserandio: www.butyoudontlooksick.com

AS Exercises *by Margaret Lewington (Physiotherapist)*

This issue features some exercises sitting in a chair. This helps to stabilise your low back and therefore help to move your upper back and rib cage. Sit tall and well supported.

1. PELVIC ROCKING

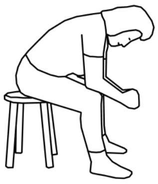
Place your hands on your knees—push gently to lift your chest, arch your back and rock your pelvis forwards. Keep your chin tucked and neck long. You can also gently take your shoulders back and activate the posture muscles in the upper back/shoulder blades.



Keep your chest up tall, but gently rock your pelvis back, so as to round your low back. You can rock forwards and back repeatedly.

2. LOW BACK STRETCH

Lean forwards and place your elbows on your knees. Rock your pelvis back, to round your low back and feel a stretch in the lumbar muscles. Relax and rock forwards. Repeat this in a rocking motion. Your chest will drop and lift a little.



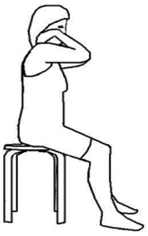
You can hold the stretch position for longer. You can also rock further forwards to increase the arch.

3. HANDS ON SHOULDERS

Sit tall and place your hands on your shoulders. If this is difficult, you can put your hands on your chest or sides/hips.

A. OPEN AND CLOSE

Bring your elbows forward, trying to touch them in the front. Allow your upper back to stretch, curl and round. Now take your elbows out to the sides, feeling a stretch on the front of your shoulders.



Sit tall and lift your chest. Your upper back may arch a little, but do not let your lower back arch too much.

B. SIDE BEND

Drop one elbow and hold it on your ribs. Lift the other elbow high. Stretch and lift as high as possible. You can also take the top hand off and reach over your head. Repeat to the other side.

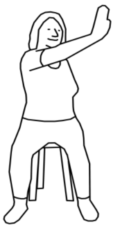
C. TURNING

Keeping tall with your chest lifted, turn to look behind, taking elbow as far as possible behind. Look at this back elbow. Repeat to the other side. You may wish to hold the turn position, breathe in and out, and then try to go a little further.

4. DIAGONAL REACH ACROSS

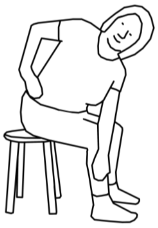
Sit tall and reach forwards and across your body in front at chest level. Look at your hand. Repeat side to side.

You can aim for 11/1 o'clock, 10/2, and 9/3



5. DIAGONAL REACH DOWN

Start with your hands resting on your thighs. Now reach down and across, with one hand, to your opposite ankle (outside if possible). Then sit back up tall.



6. DIAGONAL REACH UP

Start with hands resting on your thighs. Lift one arm up and back, a little out to the side. Look at your hand as it lifts behind you. Return to your knee.

You can combine 5. and 6. to make a long diagonal movement.

Ankylosing Spondylitis Victoria Inc Report *by Annie McPherson*

In Melbourne, Victoria we remain in coronavirus/COVID-19 lockdown due to the pandemic restrictions. Some days are better than others and we are all trying to find ways to keep ourselves fit and healthy whilst working in our home offices. Our regional members are at least able to move around and some school age children have returned to the class-rooms. As always, we hope all our readers, friends and family members remain well and safe. Our committee team have been working towards some new ideas for our AS Victoria group in a COVID+ environment. We will keep you all posted on developments as they come through. The exercise programs, articles and webinars continue in our social media online. In this edition of AStretch we bring you some ideas for self-care and ongoing management of your health as well the regular and informative articles.

- Our Ankylosing Spondylitis Victoria Inc. Annual General Meeting was held on 13 September 2020 with 6 committee and 2 members attending. This year's committee members were elected unopposed and are as follows:

  President- Annie McPherson; Vice-President- Adam Collard; Secretary- Vicky Genius; Treasurer- Paul Fallon; ordinary committee members- Shayne Van der Heide; Dionne Lynch; Maria Makris. Annie thanked the secretariat, committee and volunteers for all their efforts in keeping in touch and informed with our Ankylosing Spondylitis (AS) community over the past 6 months.

- We have more enquiries and several new members to AS Victoria via our Facebook and web pages' activity, which have definitely been boosted. We would like to welcome new members, James of Point Cook, Dionne of Traralgon and Clare of Yarraville.
- Our Christmas in July lunchtime function was held virtually on Sunday afternoon, 26th July with 7 members and committee attending. An enjoyable chat about life with a chronic condition living in a COVID-19 lockdown environment continued.
- Several of our committee members have been participating in the various patient and Health consumer focused webinars about healthcare in Australia at present.
- Our committee member Dee Lynch been busy during the COVID-19 cold winter weekends preparing several excellent articles on self-care for those with an inflammatory chronic condition. Please refer to Page 4.

CreakyJoints Australia: A new Patient Guidebook:

We are pleased to advise our AS community, our associated musculoskeletal patient advocacy group that CreakyJoints Australia have just released a new Australian guide for axial spondyloarthritis (axSpA) and AS patients. AS Victoria member, Rosemary Ainley, co-author with the team at CreakyJoints Australia, should be commended on their new online guidebook for patients living with Axial Spondyloarthritis (AxSpA) including AS "**A Patient's Guide to Living with Axial Spondyloarthritis in Australia**".

They have provided an excellent toolkit for an axSpA and AS patient trying to understand a chronic and debilitating health condition. Along with many daily management tips, they have offered explanations to navigating the many hurdles of the Australian Social Services and Healthcare systems. This is a well laid out guidebook, supported by references to relevant, up-to-date and reliable online resources. Please refer to Page 1 for Rosemary Ainley's article and link for this exciting new patient online resource.

Axial Spondyloarthritis International Federation: Workshop on Delay to Diagnosis Project:

During the 2018 ASIF council meeting in Guangzhou China, one of the high priority barriers identified by the global participants was the substantial Delay to Diagnosis, averaging over 7-9 years for most axSpA patients. As a result, the ASIF council, led by Wendy Gerhart, CSA (Canadian Spondylitis Assoc.) designed an online global workshop for ASIF member countries.

This introduction, covers the objectives and intentions of the AS community attending the workshop:

> *"The time to diagnosis of Axial Spondyloarthritis is a global issue. Although in some countries the time may be a year or two less than the average (7 years), the time to diagnosis is lengthy globally. A global goal is to reduce the average time to diagnosis; achieving this can minimise disease progression and disease burden."*

The event included leading Spondyloarthritis researchers and Health Professionals as well as ASIF mem-

Ankylosing Spondylitis Victoria Inc Report *continued from Page 9*

ber country delegates, many of us have lived with axSpA or AS most of our lives.

Although being the middle of the night here in Australia, we managed to have four delegates, including Shayne van der Heide (ASVic-patient), Margaret Lewington (Physiotherapist and AS QLD associate) Assoc. Professor Paul Bird (Rheumatologist, Sydney NSW) and myself attending. A range of topics like barriers to accessing rheumatology services, differences and similarities of delays across member communities, the role of the primary Healthcare services and differences in delays between gender and age-group experiences. The valuable information and data will be collated and analysed by the ASIF team. A second member online workshop is planned in November to discuss the outcomes and address this situation globally.

Shayne, our AS Vic committee member and volunteer provided this insight to the event:

> *"The ASIF online global meeting with like-minded axSpA leaders provided an excellent basis for robust discussion. Across the "room" of 40 people from different countries, we all seemed to have similar patient experiences in Delays to Diagnosis."*

European League Against Rheumatism (EULAR) online forum:

Last week on Monday, 12/10 was World Arthritis Day. The EULAR* held a consumer forum to discuss the impact of "**Employment risks and impacts for Europeans with RMDs**" ** during the COVID-19 recession." The link to this forum was posted by ASIF and EULAR.

> **EULAR, European League Against Rheumatism, is the European equivalent of our Australian Rheumatology Association – and it includes allied health professionals and patients, People with Arthritis and Rheumatism in Europe (PARE)*
>
> *** RMDs Rheumatic and Musculoskeletal Diseases -new terminology adopted by European Rheumatologists.*

This was a very interesting group of presentations and two panels with the moderator (who did very well too) covering many aspects of living with an arthritis chronic condition and trying to live and work during COVID-19. Even though it is based in European cities and countries, many issues remain the same as Australia – particularly, in Victoria, at this time. Very good to see a bunch of patients/consumers speaking up for us, as well as the excellent research health professionals. It will be interesting to follow if the European Union does provide some roadmaps of Best practice from successful countries on this issue.

MUSCULOSKELETAL Australia:

The Musculoskeletal Aust. (MSK Au) patient Consumer Advisory Committee (ConsAC) meeting was held in late August. The main discussion centered around the MSK AU National Consumer Survey which was released in mid-August, with a good collection of patient focused organisations spreading the word. The survey closes in Mid- October and all MSK consumers and carers are encouraged to participate.

Annie McPherson

AS Group of Queensland Report *by Graham Collins*

We hope this newsletter finds you and your family and friends in good spirits, and a special call out to our friends in Victoria, particularly Melbourne. We hope you get some reprieve in the near future.

Things are pretty quiet in Queensland at the moment. Being unable to access the RBWH pool for our Tuesday night hydro sessions twice this year did not help, although we do understand why.

Thankfully, we were able to recommence sessions in the pool with Margaret on Tuesday, 6 October and the attendance on Tuesday, 13 October was outstanding; the best numbers in a long time.

Our last social event scheduled for Tuesday, 11 August was cancelled due to lack of numbers, but we are hoping to have one in the next couple of weeks. Details of the next social event will be advertised shortly.

In the meantime, if you cannot get to the pool at RBWH on Tuesday evenings, keep up your exercise routine any way you can.

Best wishes to all.

Graham Collins

The Ankylosing Spondylitis
Group of Queensland

Calendar of Events

VICTORIA

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

QUEENSLAND

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

Due to Covid 19 restrictions there are no activities planned for the year.

If you are struggling with AS due to the impact of Covid, AStretch would encourage you to contact your health care professionals or share with us in one of the local Facebook Support Groups.

Hydrotherapy Classes

BRISBANE (QLD)

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

When: Tuesday evenings.

Time: 6:30 - 7:30pm

Where: Hydrotherapy Pool

Lvl 2, Ned Hanlon Building

Royal Brisbane & Women's Hospital

Butterfield St, HERSTON.

Cost: $15 or 10 classes for $140

Enquiries: Margaret on

0404 414 501 or 07 3376 6889

Ankylosing Spondylitis

PERTH (WA)

Sessions supervised by experienced Physiotherapists.

When: Monday evenings (Public holidays excepted).

Time: Two sessions.

Hydrotherapy pool 5:45 or 6:45pm.

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

Where: Arthritis Wyllie Centre,

17 Lemnos St, SHENTON PARK.

Cost: $12

Enquiries: (08) 9388 2199

www.arthritiswa

Facebook Groups

AS Brisbane

AS Sunshine Coast

AS Group VIC

General Information

Ankylosing Spondylitis Groups of Australia
www.asaustralia.org

Ankylosing Spondylitis Victoria Inc
www.asvictoria.org

Arthritis Australia
www.arthritisaustralia.com.au

CreakyJoints Australia
www.creakyjoints.org.au

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

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

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

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

Ankylosing Spondylitis Victoria Inc
Membership Form

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

Who we are and what we do....

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

We aim to provide the following:

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

Some of the benefits of belonging to our group:

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

Membership Details

First Name: ____________________________ **Surname:** ______________________________________

Mobile: ________________________________ **Home:** ______________________________________

Email: ____

Address:

____

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

Signed: ____ **Date:** _____/ ______/ ______

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

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

Membership Type

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

☐ **Mail out# membership ($25.00)**
☐ **Concession* Mail out# membership ($20.00)**
☐ **Email member ship ($20.00)**
☐ **Concession* email membership ($15.00)**

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

Total: $ ________________

Cheque, money order or direct deposit -

AS Victoria Inc NAB BSB : 083 399 Account : 154321878

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

Statistical Information *(Optional):-*

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

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

3. Gender **M / F**

4. Year of Birth: ______________ **5.** Preferred Language: ________________________

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

Do you have any other conditions?

………………………………………………………………………..…………………

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

………………………………………………………………………………..………………….

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