A Prescription For Exercise: New Guidelines Offer Evidence-Based Recommendations For AS

Exploring The Placebo Effect

Sex Differences In Pain
Dear Readers,

As always, it is with great pleasure that I write to you today. Our SAA continues to make great strides toward a better future for those we serve. For example, next week, I will be attending the biennial Spondyloarthropathy (SpA) Congress in Ghent, Belgium. The only SpA-dedicated International Scientific meeting in the world, this meeting is critical to the sharing of SpA advances among thought leaders worldwide. I look forward to bringing this exciting information back to you.

Because this is a small gathering of up to 250 research clinicians, the organizers are very selective in choosing speakers, and so it is with great pride that I can tell you that five of our SAA colleagues, including Drs. Reveille, Rosenbaum and Colbert, have been confirmed to present their most recent findings. Moreover, much of this work was made possible by funds released from the SAA. This is one more example of your hard earned and graciously donated dollars at work. Thank you. We will keep you posted as to next steps.

On a personal note, just over one year ago, I was diagnosed with metastasized breast cancer. The good news is that, during these past thirteen months, I have shown to be a “super responder” to the chemotherapy and other treatments that I receive every three weeks by infusion and have continued to work full time. Today, advanced cancer for the fortunate ones like me has become a treatable chronic condition with projected long term outcomes.

I can say with sincerity that I could not have done this well without having experienced firsthand the deep courage, strength, and determination of those affected by spondyloarthritis throughout the years. The spondylitis community has shown me much about how to thrive in the face of serious chronic illness. Thank you.

A few days ago, I celebrated my 20 year anniversary of service to the Spondylitis Association. You have been my stewards, my mentors and my teachers since that first day in September of 1995 when the SAA was just a two person organization.

With your continued example and unwavering support, I look forward to many more years at the helm of the organization it has been my deep pleasure to serve.

With warmest personal regards, thank you.

Laurie M. Savage, MS, FLE
Executive Director / CEO
“After suffering severe lower back pain and several other symptoms for the past three months, I asked my doctor to do some bloodwork to check for autoimmune diseases. I observed the test results online this morning and found that I had a positive HLA-B27. I began searching the internet (which is usually a bad idea) for an explanation of this result combined with my symptoms. I need to confirm things with my doctor, but clearly after reading information on the internet, including your website, I have AS, Uveitis, and possibly Crohn’s or UC. This has been a frightening day and a painful few months, but the information contained on your site has been quite informative, validating, and even reassuring. The unknown is difficult to deal with and I found the information on your site to be informative and well presented.

I just wanted to take a moment to say thank you. I’m sure you don’t hear it enough, but for people like me who are looking for quality information, the work you’re doing is VERY helpful. Have a good day and please keep doing what you’re doing.”

Stephen
Corvallis, Montana

Editor’s Note: Dear Stephen, thank you so much for taking the time to send our team kudos – especially during such a bad day. Early diagnosis and reaching the undiagnosed are among the core principals of our mission and your note sends a very hopeful message to those, who like you, are on that journey. Thank you for letting us know that our work on this crucial issue helped you in your search for answers. Please know that we are always here to offer support and information. Thank you again, and all our best to you!

“Congratulations on your animated spondylitis awareness video: ‘Could Spondylitis be the Cause of Your Chronic Back / Joint Pain?’

I have seen this format before - it is very catchy in its presentation. Somehow I am hoping the concept of "chronic inflammatory back pain" could get out in the general population more. These are the people who need to be assessed. Remember that 6% of the US population between the ages of 20 and 70 have chronic inflammatory back pain as per NHANES 2009-2010, while only 14% of these ever see a rheumatologist (as per insurance data.) Outside of rheumatology, there is little awareness of the concept of spondyloarthritis.”

John D. Reveille, MD

Editor’s Note: Thank you Dr. Reveille! We will soon be releasing our second animated awareness video, so keep an eye out for that.
The placebo effect is a phenomenon in which an inactive substance - such as a sugar pill, saline solution, or another so called ‘fake treatment’ which should have zero therapeutic impact when given to a patient as treatment - has a mysteriously beneficial effect.

The placebo effect was first observed by an American medic named Henry Beecher on an Italian battlefield toward the end of World War II. Beecher and an unnamed nurse were tending to wounded US troops when they ran out of morphine. Not having access to additional medication supplies and unable to find another solution, the nurse gave the soldier a shot of saline (salt water) while reassuring him that he was getting a potent painkiller and should be feeling much better very soon. It worked. The injection of saline solution somehow relieved the intense pain and agony, preventing shock.

In the months ahead Beecher would often duplicate this outcome when they would run out of morphine – as happened frequently near the end of the war. He reports in his writings that nearly 40% of the soldiers who received the “sham” treatment of the saline injection reported a notable lessening of their pain. The experience had a lasting impact on him making him wonder which medications and treatments were truly effective in of themselves, and which were in fact useless and simply had the placebo effect as their most effective component.

After returning home, Beecher would continue his research into the placebo effect, becoming the leading figure in reforming how we vet and test efficacy in new medications. He introduced and advocated for what is now the gold standard in clinical trials: the double-blind, placebo controlled, randomized clinical trial (RCT) and is responsible for helping usher in safer medications that work for a much greater percentage of the population, and keeping ineffective treatments and medications out of the realm of accepted medicine.

Since its discovery, the placebo effect has been something of an embarrassment to pharmacology, and a huge obstacle to pharmaceutical companies. The positive response to placebo in patients in clinical trials has similarly been viewed in a negative light as a trait related to a naïve or gullible nature in the patients. However, there is another perspective to consider as we examine the placebo effect. What can we learn from this phenomenon, and can we use its powers responsibly to improve outcomes and patient wellbeing?
Researchers at Harvard Medical School contributed much to the serious and academic consideration of this question when in 2011 they established the world’s first interdisciplinary center for placebo research - the Harvard-wide Program in Placebo Studies and the Therapeutic Encounter (PiPS,) hosted at one of Harvard’s major teaching hospitals, the Beth Israel Deaconess Medical Center. They are not, by any stretch however, the only researchers investigating the placebo effect and its implications. The newly emerging field of placebo studies is robust, and has already produced evidence of physiological changes in patients reacting to placebos.

So what exactly is at play during a high level placebo response? Research points to a number of psychosocial factors and cues.

The Doctor-Patient Interaction

This rather unquantifiable notion of the age-old ritual of medicine is still carried out in most modern doctor-patient interactions. The confidence inspiring physician in the white coat, their focused attention, comforting touch and sympathetic ear, and the reassurance that a positive interaction with a supportive medical professional can instill - all of these things, when present in the interaction, can work to build trust in the practitioner, ease anxiety, and inspire hope and optimism in the patient, triggering the start of the placebo response.

A 2008 study titled, “Components of placebo effect: randomized controlled trial in patients with irritable bowel syndrome,” sought to investigate three factors suspected to contribute to a placebo response: assessment and observation by medical providers, the placebo treatment alone, and lastly the supportive doctor-patient interaction.

The researchers separated study participants into three groups: the waiting list group - who were simply observed and their symptoms tracked, the placebo treatment group itself (in this instance the placebo treatment being sham acupuncture, where the needles appearing to be inserted into the skin simply retract into the handle and do not penetrate the skin), and lastly the “augmented” placebo treatment group - where the sham acupuncture was accompanied by a warm, supportive, and attentive patient-practitioner relationship.

The study found that the combination of the placebo treatment with the supportive patient-practitioner relationship produced the highest placebo response rate, with 62% of those in the augmented placebo treatment group reporting adequate relief, compared to 44% of the placebo treatment only group (with no supportive interactions), and 28% of the waiting list / observation-only group. The authors concluded that the patient-practitioner relationship was the most significant factor in this study, and that different components contributing to a placebo response can be progressively combined - similar to a graded dose escalation of treatment.

Patients’ Expectations and Neurochemical Functions

Using functional MRI (fMRI) and other neuroimaging techniques, numerous studies have documented the impressive effects expectations can have on brain activity and neurochemical functions. Most notable of these are studies investigating the placebo response in pain and analgesia, and movement disorders such as Parkinson’s disease.

Pain processing and pain regulation are associated with several regions of the brain, including the thalamus, insula, and the anterior cingulate cortex, among others. A number of studies have demonstrated through fMRI a notable reduction of signals in the brain’s pain-responsive regions when study participants were told they were receiving a pain relieving agent (and thus expected pain relief) even though, just like Beecher’s saline injections on that battlefield, the participants were actually only administered a placebo.

Similarly, researchers have been able to demonstrate the “nocebo” effect (the dark side of the placebo effect, in which adverse effects are brought on by the patient’s own expectations or fears.) In many studies researchers found that when participants expected to
feel an unpleasant sensation - that is when they were misled to believe that a painful event was about to occur - their brain’s pain-responsive regions were activated and signals in those regions increased, even though no painful stimuli was actually administered. All of these studies strongly suggest that many of the brain’s neurochemical functions can be manipulated not only through pharmaceuticals, but through the mind’s own expectations²³.

“…in a 2008 national survey of US internists and rheumatologists, about half of the 679 physicians participating in the survey reported having recommended a treatment primarily to “enhance the patient’s expectation of getting better.””

Where We Go from Here

So what does all of this mean for patients and physicians outside of clinical trials and experiments, and in actual clinical practice? Can components responsible for the placebo response be utilized in appropriate and ethical ways to enhance treatment outcomes? Many researchers and physicians believe so.

In fact, in a 2008 national survey of US internists and rheumatologists, about half of the 679 physicians participating in the survey reported having recommended a treatment primarily to “enhance the patient’s expectation of getting better.” The majority reported introducing the treatment as something that is not typically used for the patient’s condition, but that they believed may be of help. 62% of the physicians said that recommending such a treatment was ethical and permissible in their opinions. The survey did not report the efficacy rates of the placebo treatments recommended⁴.

Perhaps more importantly, and as we’ve seen above, attentive and supportive doctor-patient interactions can enhance the efficacy of even placebo treatments, and as other studies suggest, make real medications more effective. The nature of this particular component of the placebo response - the supportive interaction with the physician - is ethically beyond reproach, has no side effects, and improves patient wellbeing in a multitude of ways. It also demonstrates the immeasurable value and clinical significance of a truly supportive bedside manner.

“To really do the best for your patients, you want the best placebo response plus the best drug response,” says William Potter, MD, PhD who has conducted, overseen, and analyzed hundreds of clinical trials⁵.

As for the burgeoning field of placebo studies, it seems to keep expanding in multiple directions with recent studies examining the role genetics may play in a person’s susceptibility to the placebo response. Though the study of human genetic variants in the placebo response is in its early stages, some interesting initial discoveries have already been made. Of particular interest to researchers studying the genetic influence on placebo are the dopamine, opioid, serotonin, and endocannabinioid systems, as these systems are found to impact both neural and cognitive elements in a placebo effect¹. Analyzing the genetic differences within these particular systems and how they correlate with placebo responses has begun, and promises to be a worthwhile endeavor.

“…”To really do the best for your patients, you want the best placebo response plus the best drug response,” says William Potter, MD, PhD who has conducted, overseen, and analyzed hundreds of clinical trials⁵.”

References:

Dear Readers,

We need your feedback once again to ensure that we keep this magazine informative, interesting, and relevant to you. What topics would you like to see covered in future issues? What are we doing right? What can we do better? Please let us know by responding to the soon-to-arrive survey.

What did you say the last time we asked for feedback? Quite a bit actually!

We’re happy to report that many of your wonderful suggestions have already been answered with articles.

“I have enteropathic arthritis so most times info is not specific to me. Would like more on Inflammatory Bowel Disease and AS together as a dual diagnosis.”  (Addressed in the Winter 2015 issue.)

“Information about products that could help with AS.... Pillows, lumbar supports, chairs, exercise equipment, food, supplements, etc.”  (This was the inspiration for our Helpful Hints series.)

“Exercise recommendations.”  (Addressed in this very issue, as well as the Summer 2015 issue.)

“Articles about people who do NOT have severe AS. We are fortunate, but we still have problems with pain and every day activities.”  (Addressed through various Your Stories published throughout this past year.)

“Non-medical ways to manage the disease like pain management, exercises, stress management, coping with depression/anxiety. Everyone forgets we suffer with chronic pain. Pain causes stress and stress increases inflammation - a vicious cycle.”  (Addressed in the Winter 2015, as well as Fall 2015 issues.)

“I would like to see some articles about AS and diet.”  (Addressed in the Summer 2016, as well as Winter 2015 issues.)

And then there are the comments that warmed our hearts to no end, and that we can’t thank you for enough.

“Your magazine has been instrumental in helping me when I feel like giving up. I would feel so alone in struggling with this disease without your magazine. I am extremely grateful to you!”

“Continue the good work. Knowing I am not alone and my illness is not all “in my head” has been a tremendous relief.”

“I give your magazine the highest rating. You do an excellent job of informing patients and you make the information easy to understand and interesting. Keep up the great work!”

“You had me at hello.”  (This one may possibly win them all!)

Others we have on our growing list:

“It would be helpful to know more about exhaustion and brain issues. The pain I can take, but I have a hard time doing my professional work because of perception, fatigue, and memory issues from what I can only imagine is inflammation.”

“Articles that pertain to us ‘older folks’ that have advanced stages of AS.”

“More things about AS and women. Still too much discrimination toward women with AS as if we don’t matter or we are crazy and don’t have AS.”

“A Q&A column: questions from patients on issues common to living with spondylitis, answered by medical professionals (doctors, physical therapists, nutritionist, etc.)”

“More humor!! I feel better when I laugh.”

“Whatsoever category the articles on “difficult intubation” and dental advice for AS patients are in (medical management?) More of those articles on various ways Ankylosing Spondylitis changes your medical and dental experiences and how to best deal with them, those would be important. (And the past ones have been helpful!!!)”

Do we have your current email address? If not, please contact us at info@spondylitis.org to update your information, and look out for our survey shortly after receiving this issue. We especially find your recommendations and suggestions helpful so please, keep them coming!

Lastly, you are always invited to share your own story, as well as your thoughts on the magazine or a particular article by sending a letter to the editor. Send your letters to elin@spondylitis.org — she truly loves getting them and responds to each one.
Thoughts On Underdogs And Morning People And The Missing Man

By Diann Peterson

A few times a year, I’m asked to write an article for *Spondy Plus*. It’s one of the few times this introvert comes out of her hamster ball; typically I prefer to be behind the scenes, but for each issue someone on the Development staff *(that would be me and Richard)* is expected to speak up and put some words to paper.

Generally, I write about the value of philanthropy and why becoming more involved in the workings of SAA is a good thing. Occasionally, I try to float a joke or make an excuse to use a picture of a cute dog, because I think we can all use a little bit more of that in our daily lives. But, sometimes I find myself writing something that feels a bit generic; something that might have been written by the Arthritis Foundation or the Psoriasis Foundation or any of the other large scale organizations that really have very little in common with SAA.

But, the truth is, SAA is not AF or NPF. We’re a completely different animal. I’ve always known that, but sometimes it’s easy to assume that BIG is the logical goal. But I think it’s important to remember, small doesn’t equate to weak; in many cases it means quick, nimble and adaptable.

Unlike those organizations, SAA doesn’t have hundreds of employees and we don’t have government grants amassed millions. *Or any at all, for that matter.* We don’t have product endorsers or PR firms or celebrity spokespersons. **What we have is a mission.**

Simply put, we don’t have resources to waste and so we don’t.

SAA — *my SAA* — is comprised of nine people. All tucked into an office park in the shadow of the planes touching down on the runway at the Van Nuys Airport in LA’s San Fernando Valley.

Nine people form the core of the engine that drives change in the field of spondylitis worldwide. Nine people create the webinars, seminars, support groups, books, DVDs, brochures, and advance the medical research that has led to earlier diagnosis and more effective medications for all those living with the pain of a disease that affects 2.7 million adults in the US.

We don’t do it alone, of course. We have an all volunteer Board of Directors comprised of people who are committed to the cause, and a Medical & Scientific Advisory Board made up of the leading clinicians and researchers in the world. More
importantly, we have an amazing group of supporters who make it possible for us to do what we do. *(Thank you, BTW.)*

But still, when I walk into the office each morning, it’s to join eight other people to get on with the business of doing the work that needs to be done. Here’s the typical morning of the non-morning-person that is me:

The first person to greet me each day is Linda. She is our front person, our mail room guru, our go-to gal. *(Spinal Tap reference alert: if you need to “locate mandolin strings in the middle of Austin,” Linda will find them for you.)* “Morning, Linda.”

Then, I pass by Elin’s office. She’s usually not in yet, as she starts later than I do, but once she gets in, she’s always smiling, even though she’s often the busiest person in the office. She’s the Programs Director and since we’re all about programs, she rarely gets a break. And still, she does it, does it well, and does it in heels.

Then I greet Erich. He’s our most recent hire and has been working diligently refining the new interactive, gamified website that I think is going to knock everyone’s socks off. Mad skills and I can’t wait to see what comes of them. *(The new website will launch soon; stay tuned, kids)* “Morning, Erich.”

At that point, I duck into my office, drop my purse, and grab my mug and a tea bag. As I make my way to the kitchen, I pass Laurie’s office. Laurie is our esteemed leader and indisputably the glue that holds the team together. Laurie is the only boss I’ve ever had who’s made me bacon. The woman makes bacon for her staff! And no, that’s not the best of her, obviously. Laurie is the reason nine people make the mark they do. Her leadership and vision are why SAA enjoys a global reputation as being at the very cutting edge of its game.

Then I greet Robin. She’s always there before me and says “Good Morning” like she means it. Her emphasis is on the “Good.” Robin’s acknowledgment reminds me every day that, while it is undeniably morning, it’s up to me whether it’s good or not. From that point on, I typically change my greeting to include that all important word. It’s amazing how something as small as a word can change your day. But it can.

Next up, Richard. Richard is amazing; he’s Laurie’s right-hand man, works with our industry partners and major donors and still manages to devote time to Programs – running our highest achieving Support Group and recently honchoing a four-pack of webinars and a White Board Animation series to drive SpA awareness. Plus, he can start an impromptu office yoga class at any time. “*Good Morning, Richard.*”

As I pass Helene’s desk, the “*Good*” in my greeting has set in and I know it will be. I sing the Cheers song in my head when I see Helene because she really does know every donor’s name *(and ID number, and giving history, and personal preferences...)*

Finally, I move on to Inna’s desk where she sits two days a week handling the organization’s finances and ensuring we exceed every standard for transparency and accountability that any watchdog group can possibly throw at us. “*Good Morning, Inna.*”

With the first round of salutations under my belt, it’s on to the kitchen for some much anticipated caffeine and once back at my desk, I’m ready and eager to start my day alongside the group of people who have made my work-life a happy one for the past 12 years.

I walk in each day believing that mornings are things best left to other people and after a three minute walk around, I’m infused with the energy my coworkers share so selflessly. I’m so grateful to work with this amazing group of people. I’m sure the larger organizations out here have great people too, and they have many achievements worthy of pride. But at SAA, we know a thing or two about wearing many hats, turning on a dime, and doing more with less. Not to mention the power of bacon.

In closing, I have to mention Chris. He hasn’t been a physical presence in the office for some time now and won’t be again, but I can’t do a run-up of coworkers and not mention him. I’ll skip all the sweet things, we’ve already said them, but I’ll say this: Chris knew that mornings were not my strong suit and so whenever he wanted something from me, he came at me first thing, when my purse was still on my shoulder and my eyes were still sleep-weary because he knew I’d give him anything to make him stop talking. And I always did. Well played, Morning Person; well played. “*Good night, Chris.*”

*The Missing Man Formation*
NEW RECOMMENDATIONS

A Prescription For Exercise: New Guidelines Offer Evidence-Based Recommendations For AS

With all the current therapies for ankylosing spondylitis (AS)—anti-inflammatory medications, biologics, dietary modifications, and even surgery in some cases—the consensus among most is that exercise is one of the most consistently beneficial treatments for symptom relief and optimal management. In fact, seven years ago at the Spondylitis Association of America’s Atlanta Spondylitis Educational Seminar, one specialist called exercise the “granddaddy” of all therapies for AS—the one clinicians repeatedly come back to because of its time-tested effectiveness.

What has been lacking, however, are specific recommendations for exercise type and dosage for those with AS. What is required for maximum benefit? And what exactly should clinicians prescribe to their patients with AS? Now, an evidence-based consensus statement on exercise, developed by a group of Australian clinicians, helps answer these questions by providing practical recommendations to “guide sustainable exercise prescription for individuals with AS.” Published in the February 2016 issue of the journal Seminars in Arthritis and Rheumatism, the authors offer 10 clinically useful recommendations that can be used by health professionals in crafting an exercise program for their AS patients, and as a self-management strategy for individuals living with the condition.

Developing the Framework

To reach a consensus on their recommendations, the authors (comprised of 11 physical therapists—all members of an Australian AS special interest group—and a rheumatologist with expertise in guideline development and research methodology) started by independently submitting up to 10 questions deemed of significant importance, which were grouped into topics. They then conducted a literature review and analysis on each topic, combining information from published studies with the group’s collective opinion to drive the development of the recommendations.

The resulting guidelines, called “Exercise for ankylosing spondylitis: An evidence-based consensus statement” focus on the core areas related to exercise and AS: assessment, monitoring, safety, disease management, AS-specific exercise, physical activity, dosage, adherence, and setting. The authors believe that these recommendations will help “guide exercise prescription and ensure that people with AS get the best possible results for the time they invest in their AS exercises.”

10 Practical Guidelines for Exercise Prescription in AS

Recommendations 1 – 3: Assessment, Monitoring, and Safety

Assessment, monitoring, and safety are crucial components of any effective exercise program, whether for a healthy individual or for someone with an acute or chronic medical condition. These elements go hand in hand to enable clinicians to prescribe an appropriate, beneficial, and individualized exercise regimen given a patient’s specific conditions,
While most exercises are safe for the majority of AS patients, the increased potential for exercise-related injury is present for any patient with AS.

evaluate the program’s effectiveness at relieving or improving symptoms, alter the activities within the program as the patient’s condition changes, and determine if specific exercises are safe and thus unlikely to cause additional harm to the patient.

Pre-program assessment is crucial in order to determine what type and amount of exercise is most beneficial and what precautions need to be built into the exercise program to prevent potential injury. The recommendations call for exercise prescription only after an analysis of an individual’s musculoskeletal and psychosocial factors, both of which may impact effectiveness of and adherence to the regimen. In addition, thorough AS-specific measures, such as axial (spine, hip, and shoulder) mobility and chest expansion (which may be compromised in some) must be assessed and monitored at least annually, so that the usefulness of the program can be evaluated and changed as necessary.

An important part of monitoring an exercise program is being mindful of potential complications and challenges that may arise as a result of adverse events associated with such physical activity, as well as those already existent within the individual. For AS this includes potential axial and peripheral joint injuries, cardiovascular and pulmonary issues, osteoporosis, movement restrictions, and impaired balance, among others. While most exercises are safe for the majority of AS patients, the increased potential for exercise-related injury is present for any patient with AS, warn the Australian researchers.

The guidelines say, for example, that high-impact activities, such as contact sports—think football, hockey, rugby—and martial arts, may be contraindicated for patients with severe AS. Likewise, exercises that greatly challenge balance and postural stability should be assessed on a case-by-case basis to ensure their safety for the participant.

The authors stress that clinicians must consider the physical changes that may occur in their patients as a result of AS progression—the amount of ankylosis, balance and mobility changes, and susceptibility to cardiorespiratory issues—when designing an exercise program.

**Recommendation 4: Disease Management**

Whether exercise affects AS at a systemic, anti-inflammatory level or more locally at the entheses (the connective tissue between tendons or ligaments and bones,) remains unknown. The researchers did not find sufficient evidence on whether the benefits of exercise for AS patients were systemic or local. They did, however, identify two studies that demonstrated a highly beneficial effect when therapy with TNF inhibitor medications is combined with an AS-specific exercise regimen, compared to TNF inhibitor use alone. The recommendations state that TNF inhibitor therapy “can be a ‘window of opportunity’ to optimize mobility and physical fitness,” and that individuals on TNF inhibitors should continue their regular exercise program.

**Recommendation 5: AS-Specific Exercise - Mobility**

Through their literature review, the authors found “consistent evidence” of the importance of spinal mobility exercises in the management of AS. Peripheral joint mobility exercises were also noted as important. While at this time they could not recommend specific *range of motion exercises* over others, they stressed the importance of setting appropriate individual mobility goals based on assessment findings. For instance, in someone with early, or well-controlled AS, mobility goals may include restoring normal posture and full spinal range of motion. In others maintaining existing range of motion and posture may be the goal.

(*Note: Range of motion is simply how far joints can move in certain directions. Range of motion exercises are movements that take the joint through its full range of motion to help reduce stiffness, and maintain or improve the joint’s mobility.)*

**Recommendation 6: AS-Specific Exercise – Other**

In addition to maintaining or improving mobility, an effective AS exercise program should also include exercises to improve balance, coordination, muscle strength, cardiorespiratory (heart and lung) fitness, and functional fitness. The primary postural muscles that can benefit from stretching and strengthening exercises include those in the back, shoulder and chest, which can help prevent or limit kyphosis.
Though specific exercises could not be recommended across the board, the authors noted the existence of preliminary evidence favoring a few modalities, including tai chi and modified Pilates.

(excessive forward curving of the neck and spine.) Again, though specific exercises could not be recommended across the board, the authors noted the existence of preliminary evidence favoring a few modalities, including tai chi and modified Pilates. The authors stress that exercises that focus on biomechanical, or functional changes should be prescribed on a patient-by-patient basis, after assessing needs, limitations, and setting goals.

**Recommendation 7: Physical Activity**

The evidence of the importance of physical activity on good health—for everyone—is abundant. The Centers for Disease Control and Prevention (CDC) says that adults should get 150 minutes of moderate-intensity exercise (such as light aerobics, brisk walking, or swimming) or 75 minutes of vigorous-intensity exercise such as jogging or running every week, plus two days or more of activities that strengthen the major muscle groups in the legs, back, hips, abdomen, chest, shoulders, and arms. “Regular physical activity should be encouraged to promote general health, well-being, and functional outcomes,” state the authors.

While the CDC guidelines above are intended for both AS and non-AS patients, some with AS may be advised to reduce or eliminate high-impact activities to reduce the risk of injury and of aggravating their symptoms. In addition, the authors found that low-impact activities that combine mobility, strengthening, and functional training, may be especially beneficial for those with AS.

**Recommendation 8: Dosage**

Since a “one-size-fits-all” approach to exercise dosing is not possible, the guidelines call for exercise frequency, intensity, duration, and type to be tailored to each individual’s assessment findings and goals. Once the optimal level for mobility, posture, and stretching and strengthening exercises is achieved, a “maintenance” dose, rather than progression, is recommended. Consistency, the researchers say, is the most important factor. National physical activity guidelines for other types of exercise, like those proposed by the CDC, can be modified as needed.

**Recommendation 9: Adherence**

An exercise program is only effective if an individual follows it. Adherence to such a program is crucial if any individual, with or without AS, is to benefit. The guidelines say that clinicians should assess adherence in order to “encourage motivation and promote ongoing self-management.” They do not, however, provide specific recommendations on how that should be done.

**Recommendation 10: Exercise Setting**

An exercise program can be implemented in a number of settings: in the home, in an outpatient clinic, at a spa, exercise facility, or gym, or even in an inpatient hospital setting. In order to enhance adherence and optimize positive outcomes, the authors recommend that patient preference be a priority in choosing where the exercise takes place. Supervision of the exercise often enhances its effectiveness, but is not necessary for compliance or success. AS-specific exercise in a group setting and warm water exercises were noted as beneficial additions to an individual’s regular exercise routine.

The consensus statement reviewed here is the first comprehensive set of exercise recommendations and guidelines developed for AS clinicians and patients. The researchers say their guidelines are “specific enough to be clinically useful, but flexible for adaptation” for other musculoskeletal conditions, including rheumatoid arthritis, osteoporosis, and osteoarthritis. And, while the framework was written by Australians primarily for Australians with AS, the recommendations are certainly applicable to AS patients throughout the world.

Clinicians have known for years that exercise is beneficial for people with AS and that when the right exercises are performed, patients are typically better able to manage their pain and other symptoms as well as improve their mobility and function. These new recommendations will help guide clinicians on the right type, frequency, and intensity of exercise for their patients with AS. We hope you put them to use!

Further Reading:

As some of you may now by now, our small and close-knit SAA family lost a dear member some months ago. Christopher Joshua Miller passed away unexpectedly on July 5th, 2016 at the age of 41; his sudden death caused by head trauma suffered during a fall.

Chris had been with us since 2004 – having initially come on board as our Web Specialist – and whether you knew him or not, if you’ve been at all involved with SAA and our services through this past decade, you’ve been impacted by his work. From our website to our seminars, our news items and the eSUN e-newsletter, this magazine and so much more – everywhere we look today we see Chris’ substantial contributions and the rich legacy he’s left behind.

Chris was our Director of Programs from 2011 to 2015, overseeing the resources SAA offers to the spondylitis community. As emcee during those years at our spondylitis educational seminars, he made people feel welcome and valued. Back at our office, he was there with a patient ear and thoughtful resources for so many who called on the SAA hotline or wrote on the SAA forums.

Chris served as Editor-in-Chief of this very publication, *Spondylitis Plus*, from 2013 to 2015, after which – having moved to Missouri with his wife, Katie – he remained involved with SAA as an independent contractor, continuing to contribute to our website, our magazine, and more. In fact, it is bittersweet looking back on our previous, Summer 2016 issue of *Spondylitis Plus*, as the beautiful cover for that issue was designed by Chris, and would be the final project he completed for SAA.

The number of lives Chris directly and indirectly improved is incalculable. The loss to the spondylitis patient community is huge; and the loss to his family and friends immeasurable.

Today we remember and honor the life and achievements of this talented, creative, kind and caring man, and offer our deepest condolences to all who loved him.

Thank you Chris, for your passion for our cause, for your contributions to our fight, and for your friendship. You’ve made your mark, our dear friend and colleague; you are remembered fondly, and truly missed by many.
Men and women have different mechanisms that are at work in producing pain in rheumatic diseases—a little-studied and little-appreciated fact that is crucial to developing and using the right kinds of treatments, an expert in rheumatic disease pain said in a talk at the 2015 ACR/ARHP Annual Meeting.

The lack of acknowledgment of this sexual dimorphism in pain is not surprising considering that pain in rheumatic diseases in general is an area that has not been examined closely enough, said Jon Levine, MD, PhD, professor of medicine in the Division of Rheumatology at the University of California San Francisco.

*Note: Sexual dimorphism relates to the distinct physical differences (beyond sexual organs) between males and females of the same species.

“We’ve made, in many ways, remarkably little progress,” he said. “I think we seriously have missed the boat in this particular area in the understanding of pain.”

Even though gender differences in pain mechanisms are less appreciated than they should be, it’s clear that women are more susceptible to certain rheumatic diseases than men: Systemic lupus erythematosus, systemic sclerosis, RA and others have a higher prevalence among women.

One factor in gender differences in pain and rheumatic diseases, Dr. Levine said, is the role that the extracellular matrix plays as an interface between the immune system and the nervous system. But a deep understanding of the mechanisms has been hindered by the approach to research: Almost all of the data that are available in understanding these mechanisms have come from animal and human studies involving exclusively male subjects, Dr. Levine said.
Because men and women both experience the same degree of magnitude of pain, and often for similar durations, the illusion exists that the mechanisms must be the same, he said.

But there are clear indications that important differences exist, he said.

How to Think about Pain

Dr. Levine said it makes sense to concentrate on the peripheral nervous system, both in looking at rheumatic disease pain and the gender differences of that pain. In particular, it’s important to recognize the relationship between what happens in the immune system and their peripheral mechanisms.

“Immune cells produce a large number of mediators that are able to act on a large number of receptors and able to produce sensitization to a number of different signaling pathways,” Dr. Levine said. That helps explain why pain can sometimes be so hard to treat, he said.

“It’s probably no wonder that individual signal blockers, individual mechanisms, have been relatively unsuccessful in terms of really maintaining chronic control of pain in patients where the disease over time may actually change in terms of its immune and biological function,” he said.

It would help clinicians, he said, to alter the way in which they think about chronic pain—it’s not how long the pain lasts, but the mechanism of it. Thinking in terms of pain duration “gives us no insight into the biology of this pain,” and, therefore, no insight into how to treat it.

Chronic pain, he said, can come in two forms: one that can last for months or decades, but disappears when you remove the underlying cause; and another in which patients feel pain even when they’re in “remission,” with no sign of inflammation or disease, or when a patient becomes resistant to a kind of therapy that used to work.

Gender Differences

For all its limitations, research has produced some striking illustrations of gender pain mechanisms.

A key gender difference, Dr. Levine said, is in the mechanism underlying “hyperalgesic priming,” a process that leads to chronic pain. But the stimuli and pathways involved in this process vary greatly between men and women. For example, certain inflammatory stimuli—such as TNF-alpha and IL-6—initiate the process in men, but not in women.

In male rats, when male sex hormones are removed, the mechanisms involved in sensitization in the nociceptor [nerve cells that initiate the sensation of pain by sending pain signals along the spinal cord to the brain] are unchanged. In females, [the pain sensory mechanisms] are very different, with a protein kinase C-epsilon pathway that doesn’t exist in those in which the sex hormones are intact.

Studies of gender differences in the effectiveness of analgesics have been scant, but one study of the kappa-agonist, nalbuphine [a synthetic opioid medication indicated for moderate to severe pain] —led by Dr. Levine—shows a striking disparity. Women on a 10 mg dose of the drug had pain levels improve dramatically and continue to be improved; however, in men, the drug led to some relief at first, but ultimately resulted in worse pain levels than baseline.

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Further study found that a mix of 5 mg of nalbuphine and 0.4 mg of naloxone [an opiate antagonist that blocks or reverses the effects of opioids, and is frequently used in cases of overdose] led to pain relief that was similar in both men and women. This indicates that a completely separate [opioid] receptor is at work in men, Dr. Levine said.

“There’s a second receptor that these drugs work in that makes pain worse,” he said. “Dramatically different between men and women.”

Dr. Levine expressed wonder that 5,000 years after opioids began to be used for pain relief, we only began to recognize gender differences about 20 years ago. Even now, he said, there is still an element of “it’s all in your head,” when it comes to women and pain, he said.

“Still, to this day,” he said, “I think that male patients are treated very differently from female patients.”

Further Reading:


"For all its limitations, research has produced some striking illustrations of gender pain mechanisms."
I am a 37 year old female with ankylosing spondylitis. My symptoms began when I was eight years old and I was finally diagnosed at 28. I take the management of my disease very seriously, most likely because for over 20 years my pain was dismissed. It was implied directly and indirectly that I was just really sensitive, overly dramatic, or otherwise unable to handle the aches and pains of normal life; that nothing was wrong with me.

When asked to write about my personal experiences as a patient who takes an opioid, I didn’t know whether I should do it. I felt proud to be asked, but then immediately panicked. How can I, a mother going through a divorce, put my name to such a topic? How could I risk exposure and public judgement by unapologetically recounting my experiences? That was the moment I knew I had to do it for everyone like me who is simply too afraid to discuss this topic.

After my diagnosis, I found the incredible resources of SAA. When I learned that my area didn’t have a support group, I volunteered to become the group leader. I absorbed the information in my “SAA Group Leader Binder” and then scoured libraries, book stores, and the internet to try to understand what was happening inside my body. I participated in research trials with the top researchers in ankylosing spondylitis. I tracked my labs, journaled life and dietary changes, and everything else I could think of in my search for the direct causes of my flares and pain.

In 2008, I began trying different kinds of medications: NSAIDs, DMARDs, and then biologics. By the end of 2009, after failing two of the three biologics available at the time, I started taking hydrocodone for pain relief. This was a massive decision for me. I am the type of person who has never had detention; I don’t drink alcohol – not even socially; I have never done drugs and to my friends’ dismay never caved in to peer pressure, even in college. I hate confrontation so much that I always follow the letter of the law, and yet I decided to start taking a narcotic of all the evil things!

What I found in hours was relief. Never have I been totally pain free, but it took the edge off so my brain could
Taking narcotics feels dirty. It is a shameful secret I keep closely guarded now.

actually think about something other than how much I hurt. Hydrocodone has given me back a quality of life that no other drug, diet, herbal supplement, exercise, or old wives-tale I have tried, and TRUST ME, I have tried them all.

Still, taking narcotics feels dirty. It is a shameful secret I keep closely guarded now. I learned the hard way with a friendship I had for two years. This woman’s son and my son shared regular play dates. One day she was telling me that if I would just go gluten free like she had, all my symptoms would disappear. This was not new advice from her and you can only hear it so many times before you pop.

During my “pop” and in trying to explain for the hundredth time that I did go gluten free for a long time with no changes, that I have had two gut biopsies check for gluten intolerance, Crohn’s disease and celiac disease - as I tried to explain to yet another person that spondylitis is a disease - not a consequence of poor lifestyle choices, that it is an incurable, progressive disease that even the most powerful medications have done little to alter the progression of and that only hydrocodone has given me back a small degree of quality of life…. Addiction is indeed a horrible problem in our nation. I understand the need for increased enforcement to try to solve the problem, but everyone has seemed to have forgotten that even exercise can become an addiction to someone who has an addictive personality. Since hydrocodone’s reclassification as a Schedule II drug in 2014 I’ve experienced some difficult and frightening things.

When you take narcotics for pain relief you are branded a criminal. You are made to justify and prove your innocence to everyone who knows the secret: doctors, lab technicians, pharmacists, loved ones, colleagues - even yourself at times.

I let it slip. My secret was out and my greatest fear unfolded before me. She said, “You mean to tell me you take prescription pain killers and have been around my child?! I am sorry but my son will never be able to come over to your house again unless I am there.” I was devastated and have never told another friend again.

When you take narcotics for pain relief you are branded a criminal. You are made to justify and prove your innocence to everyone who knows the secret: doctors, lab technicians, pharmacists, loved ones, colleagues - even yourself at times.
Fast forward to 2016. The CDC has new, more restrictive guidelines on opioid prescriptions for chronic pain. Emergency rooms are starting to declare themselves “no narcotics” facilities. Across the nation, patients like me are frankly terrified. Not because we’re addicts and afraid we won’t get our high, but because without the pain medications we need, our quality of life will greatly suffer.

Since the new guidelines something else interesting happened to my doctor. As with all doctors, she can only order Schedule II prescription pads from the government, and can only order five at a time. She placed her normal order and it didn’t come. For four weeks. When the order finally arrived, she only received one prescription pad. All of her rheumatology patients, including me, had no access to pain medications for a total of six weeks.

Accordingly, each of us had to make the following phone call to our primary care physicians’ office. “Hey, um, funny thing just happened. You see, my rheumatologist normally prescribes hydrocodone for me and, um, the government didn’t send her any prescription pads and her office told me to call you guys and have you write my prescription for the next month or so until she gets more.” REALLY??!! How does that sound? Can you imagine how it makes a person of my sensibilities feel?? Did I also mention this all happened on a Thursday afternoon? The receptionist said, “I’m sorry Dr. So-and-so won’t be back in the office until Monday. We will talk to the doctor and get back to you.”

Here is the problem. I have taken this medication as prescribed, or at a dose less than prescribed, every day for years, and now I had a day’s worth of medication but three days to go until I might be able to get my refill. I am not an addict but my body has developed a physical dependence through the years. I was going to have to go into withdrawal. So then guess what? I became a criminal. I asked my closest friends to check their medicine cabinets to see if they had any; they did and I took them. That was the first and only criminal act I have ever participated in.

On Monday, my primary care doctor called and filled the script for me. When I picked it up she told me that they have had to do this at an alarmingly high rate lately and didn’t understand what was going on.

When I saw my rheumatologist a month later I demanded answers. I told her the truth of needing friends to get by and said, “I have never done that in the eight years that I’ve taken this medication and because of the government I didn’t have a choice.” She said, “Neither did I and all of my patients had to go through this same thing. It’s horrible and there was nothing I could do.”

In order to have a small increase in the quality of my life, to nudge my pain from a seven or eight into a four or five I feel like I’m looked at as a criminal, or only slightly less insulting - as someone who just “can’t handle it.”

I have been unfairly judged and labeled by close friends and even family. I suspect that even as you read this you too have thought… “hmmm yeah but what is she really like?” I have had to sign my right to privacy away through a pain management contract. I have been left without medication through no fault of my own nor my doctor’s. I have endured eight years of peeing into a cup every four months to continuously prove my innocence.

As tougher regulations and additional restrictions keep being levied on chronic pain patients, and physicians who prescribe our medications, I feel that I must share my story. I must share mine because it is often too risky or difficult for those who need opioids to do so. I pray that perhaps this article reaches someone who will begin to consider what is happening on the ground to chronic pain patients who rely on these medications.

If taking hydrocodone at the prescribed dose and frequency for eight years is a criminal act, then I am a criminal but I am NOT an addict. I am not the problem and neither are the millions of other chronic pain patients who use their medications responsibly and are compliant. Please stop treating us like addicts, like ‘less-thans,’ like criminals. I am simply in pain and hydrocodone helps me.
Corporate Support

The corporate membership program provides a way for the Spondylitis Association’s pharmaceutical members to positively impact the lives of those affected by spondylitis by contributing to SAA’s general operating budget. SAA also receives additional corporate support for special - and costly – programs, such as our live patient educational seminars.* The following pharmaceutical companies are current corporate members.

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