Q&A With A Medical Professional: Physical Therapist Edition

Fatigue in Spondyloarthritis

Your Stories: A Letter to SAA

Spondylitis Association of America™
Dear Readers,

It has been said that results are the strongest drivers of motivation. That our successes support our purpose; enhance our sense of belonging; and encourage continued motivation. If that is true, the spondylitis community has every reason to plow ahead with heightened purpose and renewed incentive. The successes we have achieved together are significant, and serve to highlight the lengths to which we can climb when we possess the necessary drive and work together to present a united front.

I’d like to take a moment to remind you of just one way in which your support directly helps to improve quality of life and bring, or restore, hope to the hundreds of thousands affected by spondylitis.

The shortage of doctors, especially rheumatologists, is a concern that dramatically impacts the lives of people diagnosed with rheumatic disease. Many patients must wait months to see a rheumatologist, which delays treatment and has a negative impact on their health.

With your critical financial support, SAA is encouraging early clinical researchers in rheumatology, already with a significant published body of work to their name, to commit to axial spondyloarthritis going forward in their careers. By funding their research and inviting them to attend significant scientific meetings, SAA is working hard to bring the next generation of rheumatology professionals up through the ranks in order to address the decline of specialists trained to treat a growing population of patients with rheumatic disease.

We have been told by many of these early career investigators that the funding arrived just at the right time and allowed them to continue their work, and with the results, go on to seek more significant funding by more powerfully endowed institutions.

We will be inviting a new group of young investigators to attend SAA’s third Unmet Needs Conference on the NIH campus in Bethesda, Maryland on September 13th and 14th. If even one promising new researcher is persuaded to direct his or her focus to spondyloarthritis, it will be a hugely successful result.

And if results are the strongest drivers of motivation, I hope you feel as motivated as I do right now.

Thank you for everything you do in support of our shared mission.

Laurie M. Savage
Executive Director
**FEATURES**

<table>
<thead>
<tr>
<th>Page</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Q&amp;A With A Medical Professional: Physical Therapist Edition</td>
</tr>
<tr>
<td>9</td>
<td>Fatigue In Spondyloarthritis: Identifying And Addressing Causes</td>
</tr>
<tr>
<td>16</td>
<td>Your Stories: A Letter To SAA</td>
</tr>
</tbody>
</table>

**ALSO IN THIS ISSUE:**

<table>
<thead>
<tr>
<th>Page</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Some Things Are Bigger On The Inside</td>
</tr>
<tr>
<td>12</td>
<td>The Laurie Savage Lifetime Achievement Award</td>
</tr>
<tr>
<td>14</td>
<td>Getting Intimate With Spondyloarthritis</td>
</tr>
</tbody>
</table>

“Dear Spondylitis Plus,

I’ve lived with AS for 40 years, finding my way before there were biologies and before the internet - but most importantly, before there was a meaningful or hopeful conversation about AS. Because of this, I shut out the medical and scientific world for the first 30 years or so, despite being an academic who is always on the hunt for new knowledge. I was unwilling to be scared by the rampant ignorance and dire warnings, and uninterested in complicated medications that did too little.

Now in 2017, I am grateful for so much: the therapies and transformations I found on my own, the breakthroughs in science and pharmacology, and the startling shift from being alone with AS to joining such a vibrant and increasingly visible community. Having just read every word in the Spring 2017 issue, SAA and Spondylitis Plus are also at the top of my list. In 20 pages, I grieved and celebrated, studied and analyzed, and breathed my own expansion through haiku and stories of a desert transformation. I have new answers and new questions that extend from my genetic code to the politics of making change. These days, I find more healing in this kind of integration than from any one drug or technique. Thank you for the whole-person vision that you hold, and the leadership, tenacity, and willingness to make a difference.”

~ Diana Kardia, Ph.D. Scottsdale, AZ

**Editor’s Note:** We’d like to share a few comments here from our most recent Spondylitis Plus Reader Survey. Please know that these responses, and your letters to the editor, are incredibly important to us, and play a role in shaping the stories we cover in future issues. We not only read every single one, we catalogue them for future reference.

“Dear Spondylitis Plus,

I’ve lived with AS for 40 years, finding my way before there were biologies and before the internet - but most importantly, before there was a meaningful or hopeful conversation about AS. Because of this, I shut out the medical and scientific world for the first 30 years or so, despite being an academic who is always on the hunt for new knowledge. I was unwilling to be scared by the rampant ignorance and dire warnings, and uninterested in complicated medications that did too little.

Now in 2017, I am grateful for so much: the therapies and transformations I found on my own, the breakthroughs in science and pharmacology, and the startling shift from being alone with AS to joining such a vibrant and increasingly visible community. Having just read every word in the Spring 2017 issue, SAA and Spondylitis Plus are also at the top of my list. In 20 pages, I grieved and celebrated, studied and analyzed, and breathed my own expansion through haiku and stories of a desert transformation. I have new answers and new questions that extend from my genetic code to the politics of making change. These days, I find more healing in this kind of integration than from any one drug or technique. Thank you for the whole-person vision that you hold, and the leadership, tenacity, and willingness to make a difference.”

~ Diana Kardia, Ph.D. Scottsdale, AZ

**Editor’s Note:** We’d like to share a few comments here from our most recent Spondylitis Plus Reader Survey. Please know that these responses, and your letters to the editor, are incredibly important to us, and play a role in shaping the stories we cover in future issues. We not only read every single one, we catalogue them for future reference.

“I would like to see articles/survey responses from readers on "real life" spondylitis questions, such as, ‘Do you see a pain specialist? What works for you in terms of medications and other treatments? What doesn't work?’ I see and hear many stories leading up to diagnosis, but not as many about what happens after, and what's working treatment-wise.”

~ Anonymous

“Thank you for the emotional support in each issue. I really appreciate what you are doing! This disease alienates and your magazine helps me realize I’m not alone in this fight.”

~ Anonymous

**LETTERS TO THE EDITOR**

We want to hear from you! Send your thoughts, questions, opinions, and rebuttals.

Please send letters to:
Elin@spondylitis.org
Letters to the Editor/SAA
P.O. Box 5872, Sherman Oaks, CA 91413

Please note that we reserve the right to edit for space and clarity.
I know that activity is good for me since I have AS. However, when I try to work out (even lightly,) if I ride my bike, or try to do much of anything physical there is always a chance that I can feel worse pain after being active. How can I remain active without paying the price with pain afterwards?

Staying active with AS is truly one of the bigger challenges we face. Our bodies can react more violently and with greater rebound than the average person’s does. The trick is figuring out where that threshold is and how much we can do without crossing the line. This can be incredibly frustrating at
Staying active with AS is truly one of the bigger challenges we face. Our bodies can react more violently and with greater rebound than the average person’s does. The trick is figuring out where that threshold is and how much we can do without crossing the line.

Times because that line seems to be variable; it moves. But, a general sense of how much activity you can do can be gained through experience and sometimes with the guidance of a professional who is trained in exercise. In this context, that trained professional is generally a physical therapist with some experience working with people with AS.

Some ways to consider increasing your activity is by working on the activities you already do without flaring up or increasing your symptoms. Whatever it is you already do, whether that is walking or a five-minute bike ride, use that current activity as a baseline and increase that by 10% - 20% per day. If five minutes of walking is all you can tolerate, then six minutes is a 20% increase. And while that may not sound like very much, 20% of six minutes is a little over seven minutes. 20% more than a little over seven minutes is eight and a half, and 20% of that gets you to 10 minutes. So, in only a few days you can essentially double the time that you’re tolerating your activity, provided you don’t experience any increase in symptoms.

However, and this is important, what will end up happening is that you will eventually hit your threshold at some point. That means that you will experience symptoms. The key here is really to creep up on your threshold so that you don’t go into a full-blown flare. If you notice that at 12 minutes you start to get a little sore, then back down to the activity level prior to that, 10 minutes, that didn’t bother you. Maintain that level for a few days after you have taken a day or two off and gotten your symptoms back under control. The key here is to be truly objective and to track the amount of time you are doing your chosen activity. This method can work fairly well for resistance training and other activities, as well. To be a bit more conservative you could consider 10% increases until the time at which you start to experience your symptoms, or you just get tired. Again, the key is to edge up against your threshold and figure out where exactly it lies, in order to continue working at about 80% of your current capacity. Maintain at 80% for a week or two to allow your body time to adapt. After that time, you can resume the 10% increases until you hit your new threshold.

But, you are correct in that the most important thing here is that you do some kind of physical activity. It’s what our bodies are built for. It’s just a matter of sensitivity really and the rebound of symptoms that we experience and trigger with this disease. You’re trying, again, to sneak up on your threshold and learn where that is without going over. Once you establish that, being very objective, tracking your activity and progress, and being truly disciplined about your tracking and implementation, this process can help you remain more active over a longer period of time.

Q: I am 44, have had AS for more than 20 years, and have been taking Enbrel for the last seven or so years. My pain is manageable -- I can still play and enjoy non-contact sports, but my range of motion in both my back and neck is limited. Sitting on couches can also be uncomfortable (I weirdly prefer straight back chairs.) Now that I have my pain under control, is there anything specific I can do to slow the progression of the disease and maintain or maybe improve my range of motion?

A: The coolest thing about our bodies is that they adapt to stresses. This can be used to our advantage by working on exercises specific to your postural and range of motion issues, including flexibility and strengthening exercises. When we don’t do additional strengthening and flexibility exercises, then our bodies simply adapt to other stresses we put them through, like the sitting and the harmful static postures that we’re in each day. These stresses are compounded by gravity. We are subconsciously fighting gravity every day, as it tries to squish us into the floor. Learning and doing exercises designed to improve spinal flexibility in the right direction and to strengthen in order to hold and maintain gains, against the incessant gravitational burden that we live under, is one way to make headway and progress against the
stiffness and postural issues that we experience. Strength simply cannot be underestimated. When strength is worked on, in the right positions and postures, along with exercises designed to maintain mobility, the exercises go a long way toward combating the effects of gravity, improving range of motion, and reducing stiffness.

The challenge here is that everyone is a little different. This includes their tolerance for exercises, particularly strength exercises, and their threshold before flaring up and exacerbating symptoms. There should also be considerations around anatomy and progression of the disease. So, for people with AS and related conditions, it is highly advisable to consult a skilled physical therapist who is familiar with the AS disease process and the complications that could arise from it, and ask them to design an exercise program to meet your specific needs. In crafting a personalized exercise program, they should be sensitive to your particular issues, including the disease and medications, as well as your personal goals for flexibility and strength. This does not mean we, any of us, will get our 18-year-old bodies back. However, while we may not be able to stop the progression of the disease process, we can certainly counter some of its effects.

There are also some general things everyone can and should do:
To begin with, sit up straight. This is likely why you prefer straight back chairs. A little support at the low back, a small pillow for example, can help prevent the slouched position we experience sitting on most couches or chairs. Simply paying attention to our standing and sitting postures is a good first step.

Next, change positions frequently – stand up, or reposition yourself in some way. Doing this every 15 - 20 minutes ideally can help offset the effects of static postures, which we now know are not only bad for our spines, necks and backs, but are also detrimental to our cardiac and respiratory health. Holding your phones and devices up so that you can keep your neck in a more neutral position is a simple way to avoid the gravitational stresses associated with holding the weight of your head out in front of your body.

In conclusion, limit the harmful stresses you don’t want, while applying therapeutic, beneficial stresses to achieve greater strength and flexibility, and the posture that you want.
Some things defy description and some things don’t follow the rules of science. Some things are just larger than the sum of their parts. If you’re lucky, you’ll come across one sometime in your life; if you’re very lucky, like me, you just may come across two.

Twenty three years ago I was apartment hunting and having not a bit of luck. I pulled up outside of a small, five-unit building at the end of a dead end street. The neighborhood was a bit sad; the street even more so. At the time, the building dead-ended at a junkyard, complete with actual junkyard dogs and razor wire atop the wall.

There was also a colony of feral cats – perhaps as many as 60 of them. I love cats; I had three of my own at the time, but 60 was a bit much. I instantly knew I couldn’t live there on a dare. It was just too run down, too derelict, too depressing.

Had it been an open house, “stop-in-any-time-you-like” kind of thing, I never would have gotten out of my car; but I had an actual appointment with an actual person and I wasn’t going to stand him up, so I reluctantly fought my way to street parking and made my way in, prepared to waste my time in the interest of being polite.

Crossing the street to the property, I took in the postage-stamp-sized lawn and noted the small umbrella table and chairs, the many ceramic animal statues, the wind chimes in the perfectly manicured trees and the large wooden sign proclaiming, “This Is My Happy Place.” “Hmm, can’t imagine it being mine,” I thought.

As I walked down the narrow walkway to the stairs up to the vacant second story apartment, I spied a Barbie-sized garden, the whimsical signs identifying the various herbs and veggies being grown, as well as many well-tended flowers and shrubs. The neighborhood was struggling but clearly someone loved this building very much. My reluctance faltered. But not too much.
Once I met the landlords, heard about the length of tenancy of the other four inhabitants, and saw the spacious, impeccably clean apartment, I realized that, for better or worse, I was home.

From a distance, it didn’t impress. But like the magical things in the list above, it was “bigger on the inside.”

Twenty three years later, the neighborhood has improved, the junkyard and its resident dogs are gone, and all the members of the feral colony have been spayed, neutered, and adopted out to good homes.

But the Happy Place sign is still here and so am I.

Ten years after finding my home by accident, I found my calling by accident. A friend knew I was unhappy in my then job and forwarded me an ad he found on Craigslist. The ad was de-indentified, revealing only that it was a nonprofit in Sherman Oaks that specialized in a disease called ankylosing spondylitis. (Talk about hiding in plain sight!) Not terribly surprisingly, I’d never heard of the disease. And also not surprisingly, it wasn’t difficult to track down the name of the organization.

The ad directed applicants to respond to an outside agency but after finding SAA’s website, I perused the staff listing and sent my resume off to the person I most felt would be my potential supervisor, were I lucky enough to get the job.

While I waited with crossed fingers for a call, I absorbed everything I could from the website and came away convinced that there must be about 300 employees in chapters around the country. While the site didn’t say this, I was sure there was no way the folks in the very small staff listing could possibly have made this much of an impact on the world. And I loved what I saw. In short, I wanted this job very much.

And, thrillingly, I got an interview. And then I mapquested my way there (it was 14 years ago, Siri was still in diapers,) and parked my car at a rundown looking building that did anything but impress. I walked in, took in the shabby, moldy smelling lobby, and continued to be unashamedly unimpressed.

And then I met with Jane Bruckel, the organization’s co-founder and I remembered why I’d been impressed in the first place. I asked about the chapters and was told there were none. “What about the other offices, the satellites?” “No, it’s just us.” Really?

Now I was completely intrigued. How did 11 people do what I’d seen on that website? And how can I become one of them? Once again – SAA was bigger on the inside.

Thirteen years later, it’s more like eight people, and yet the footprint is larger than ever before. SAA enjoys a well-deserved, international reputation as a leader in the field. I’m happy to say that we’re in much better offices, with no mold, and that our current leader, Laurie Savage, is making sure that we continue to impress, more so than ever.

“Bigger on the inside” is when something looks small at first glance but actually over-performs. Once, I thought it was magic, like Mary Poppins’ carpet bag or the Weasley tent. Now I see that SAA is bigger on the inside because of the commitment of its members. We were never 11 people, or eight people; we’re thousands of people. This is why your donations to SAA go as far as they do. SAA’s strength rests in the power of its supporters, members, and friends; the health advocates who work tirelessly for the cause; the volunteer fundraisers who dedicate their time and energy to fueling the engine; the donors who give thousands of dollars per year, and the ones who give $10.

And we couldn’t do it without each and every one of you. You make the magic happen and your continuing support will ensure that SAA remains a Happy Place for everyone who needs one.

So, come on in; it’s bigger on the inside!

spondylitis.org/donate
Fatigue In Spondyloarthritis: Identifying And Addressing Causes

While fatigue is not unique to spondyloarthritis, it is a rather common symptom of it, and one that doesn’t often receive the attention it deserves. Fatigue can negatively impact one’s work, social life, relationships, ability to focus, and even emotional state. To successfully treat fatigue we must first identify and untangle its often-multifaceted causes and tackle fatigue at its source. 1

Speaking with your rheumatologist about your fatigue is the first step. Only after your particular causes of fatigue have been identified, can those causes be addressed, and appropriate changes made to help lessen fatigue. According to rheumatologist Lianne S. Gensler, MD, common causes of fatigue associated with spondyloarthritis include:

**Uncontrolled systemic inflammation and disease activity** 1

Studies show this to be the singular factor most closely associated with fatigue in spondyloarthritis. 2, 3 When inflammation is not well controlled, the body must use energy to deal with it. The release of cytokines in the process responsible for inflammation can produce the sensation of fatigue, as well as mild to moderate anemia in some cases – which can also contribute to fatigue.

This is something your rheumatologist should address with proper treatment. A change in medications may be warranted in some cases. When inflammation is well controlled, and disease activity properly managed, fatigue can lessen and energy can improve. If fatigue is caused by uncontrolled inflammation, it is often among the first symptoms to respond to treatment. 1

**Not sleeping well at night** 1

This is often caused by uncontrolled pain, stiffness, inability to get comfortable, etc. Here again it is important to identify the particular causes of sleeplessness, and treat them appropriately. When symptoms such as pain and stiffness are appropriately treated, sleep often improves, and fatigue diminishes.

"Fatigue can negatively impact one’s work, social life, relationships, ability to focus, and even emotional state."
Besides causing fatigue, not sleeping well can also increase pain, creating a feedback loop of pain causing sleeplessness, which then causes more pain, and so on. For this reason effective pain management is crucial in addressing fatigue.

Other things to help bring about better sleep include slowly increasing physical activity - which can help by tiring the body, helping with stiffness and pain, as well as reducing inflammation. (*Please see our ‘Q&A with a Physical Therapist’ piece on page four for guidance on doing this safely and effectively.*)

Practicing good sleep hygiene is also important. This includes avoiding caffeine and other sleep disruptive foods or drinks late in the evening, establishing a regular and relaxing bedtime routine, creating a comfortable and calming sleep environment, and considering the use of items to block out light and disruptive noises if needed.

**Depression**

Depression also causes fatigue directly by lowering energy levels, as well as indirectly by interfering with sleep. Depression lowers serotonin levels, which, among other things, helps regulate our circadian rhythm - the internal body clock controlling sleepiness and wakefulness. As such, depression is often linked with insomnia, while lack of sleep can worsen depression. Those with chronic illnesses, including spondyloarthritis, are more likely than the general population to suffer from depression. There is also a feedback loop between pain and depression, with each making the other worse.

Depression can be short lived, or chronic, and should be treated by a skilled medical professional, as would any other medical condition.

Other causes of fatigue may include untreated anemia, and thyroid diseases, among other medical causes.  

**Preventing fatigue**

Lastly, staying healthy and being active can *prevent* fatigue. Healthy eating habits can increase and maintain energy, as can regular exercise. As a bonus, exercise itself is anti-inflammatory, while smoking can increase inflammation.

In conclusion, it is important to note that fatigue is often a manifestation and indicator of underlying issues, and other under-treated symptoms. As such, it is often a clue that something is amiss and requires the attention of a knowledgeable physician.

**References:**


Community Voices: Conversations On Fatigue

“I’m always moving through molasses and it takes endless internal self will to do anything. So not only are you physically exhausted, emotionally you are always drained.”
~ Helena

“For me, fatigue slows down all my processes, including physical and brain functioning. All my symptoms are heightened when I’m having a fatigue-flare, and the flare itself impacts all my other symptoms. I have yet to find a way to help fatigue, but something that makes it worse is trying to push through responsibilities. I absolutely have to listen to my body and slow down until I’m back at my baseline. Until then...the dishes, the phone calls, the litter box all have to wait.”
~ Charis

“Like living in a fog. Like having to will yourself out of bed. Like having to rest after doing a small task. Like wanting to sleep all the time. Like being too tired to be tired. Like being too tired to watch a movie because you keep falling asleep.”
~ Stuart

“The fatigue is awful because it limits my life so much. I feel overwhelmed and depressed because I’m missing so much. Thankfully it comes in bouts and I have good stretches without it. And I do have doctors who listen now. That is KEY!”
~ Melissa

“It’s the tiredness that lingers even after a nights (restless achy) sleep. It’s living in slow motion. It’s trying to “perk up” but realizing you can’t. It’s like trying to walk through water every minute of the day. It’s living life on slow speed, when your heart wants to fly and be free...but can’t...”
~ Donna

“Mine is caused by not being able to sleep. Day after day of no sleep! For me finding a pool at YMCA or a kind friend with a pool relaxes me beyond belief.”
~ Carla

“I can’t sleep even though I’m exhausted. I lay awake listing all the things I will get done the next day, but then I’m so tired I can’t get anything done!”
~ Cindy

“It feels so heavy, weighing me down physically, mentally and emotionally without end. I feel so guilty for not being the person I was before the disease completely took over and becoming a burden to my family and friends.”
~ Amy

“Others live in, what I call, “The land of the living.” I remember what it was like to live there. Clear mind, fluid thoughts, laughter, contributor. Chronic pain, vertigo, fatigue, and brain fog leave me more asleep than awake. I see those in the land of the living. I pretend to be normal, because I look healthy, but I feel 90 and I’m not yet 50.”
~ Karen

“Constant pain causes physical and mental fatigue. The best therapy I have found to combat all these symptoms is water aerobics in a heated salt water pool, and yoga. Keep moving!”
~ Judy
The Laurie Savage Lifetime Achievement Award was created in 2017 to honor the contributions of individuals to the field of Spondyloarthritis. The award is named for Laurie Savage, long-standing Executive Director of the Spondylitis Association of America (SAA). Laurie has been instrumental in organizing the professional community to further the cause of spondyloarthritis through SPARTAN, first as a program of the SAA, and later, as an independently incorporated organization.

Memo

To: The SPARTAN Board of Directors
From: Lianne Gensler, MD
Re: The Laurie Savage Lifetime Achievement Award

I would like approval to create a lifetime achievement award in Spondyloarthritis in the name of Laurie Savage [The Laurie Savage Lifetime Achievement Award]. This first award would be presented to Laurie in her honor at the May meeting. As you know, SAA was the parent organization for SPARTAN and Laurie, in a sense, our parent figure. It was really with her encouragement and support that we incorporated several years ago. Though we are now independent, SAA still stands as a role model for SPARTAN in many ways. Laurie has given a lifetime of work to SpA, both in support of patients and research. She has been a visionary in the field and has given SpA a face in North America, when organizations representing more broad rheumatic diseases did not.

From the Desk of Michael Weisman, MD

- Laurie has taken the SAA to a new level from the original hard work done by Jane Bruckel. Her love and care for people have made this difference–she makes us all connect to the mission of SpA in a very personal way. Most of all she makes us feel welcome, needed, and important–that is a great tribute to her success. Having a leader like Laurie is unusual and so wonderful. We love her.
A Note from Walter Maksymowycz, MD, FRCP (C)

The first thing that always comes to mind is Laurie’s constant passion for the well-being of people living with spondyloarthritis.

In 2003, SAA convened a network of medical professionals in North America who were dedicated to scientific research, awareness and treatment of spondylitis and the Spondyloarthritis Research and Treatment Network (SPARTAN) was born.

Under the SAA, SPARTAN grew to include diverse thought-leaders contributing to the field of spondyloarthritis, including rheumatologists, radiologists, basic scientists and geneticists, methodologists, epidemiologists, patient research representatives, and biopharmaceutical industry representatives.

SPARTAN operated as a committee of the SAA for ten years until the group obtained its own nonprofit designation in 2014 and continues to work closely with these preeminent researchers. SPARTAN’s work is important to the future of research in this country, because they are instrumental in educating the next generation of rheumatologists and helping to foster an interest in the SpA group of diseases.
Let’s not hold back on this. You’ve got Spondyloarthritis and your back and joints hurt, a lot. You’ve lost some flexibility and simply can’t get into the positions you used to be able to. Furthermore, what with the fatigue and bouts of depression, you don’t feel like doing “it.” But, you are still young and you know it’s healthy for couples to have regular sexual intercourse. What has to be done?

As a married man of close to 44 years, living with Ankylosing Spondylitis (AS) for nearly 36 of them, I have faced the challenges of keeping my relationship intimate and romantic. That’s why a presentation by Iris Zink, BSN, MSN, NP - “Sex and Intimacy in Chronic Disease” presented at the American College of Rheumatology annual meeting in Washington, DC this past November truly resonated. As a nurse practitioner specializing in rheumatology, Ms. Zink noted that sexual dysfunction is often the first manifestation of physical illness. Yet, few health care practitioners bring up the subject with their patients, many of whom are also too embarrassed to talk about it. They shouldn’t be.

Ms. Zink’s message is that sexual intimacy doesn’t have to involve intercourse, pointing to the fact that the brain and the skin are the largest sexual organs. A lot of intimacy can be enjoyed by hugging, caressing, and sexual stimulation that does not involve intercourse. In some cases, people have to overcome cultural or religious taboos to practice forms of intimacy that they may otherwise regard as out of bounds. Everything about sex and intimacy is normal, and some patients may need to be taught how to be more creative.

Communication between partners is crucial, as is a willingness to experiment. In the Facebook group of the Canadian Spondylitis Association, there have been discussions on intimacy and finding a position that is not painful. The missionary position (man on top) is painful for both men and women with AS, so the cowgirl position (woman on top) may be better. A physical therapist may be required to provide treatment for functional activities, such as the female AS patient Ms. Zink came across who admitted that she could not open her legs wide enough to allow for sex. Physical therapists can also offer advice on modifications in positioning.

A healthy sexuality, of which there are many forms, is key to
"Any sexual dysfunction such as those caused by disease or medications can impact not only one's quality of life, but lead to frustrations and a backing away from intimacy."

a normal, happy relationship. Any sexual dysfunction such as those caused by disease or medications can impact not only one's quality of life, but lead to frustrations and a backing away from intimacy. This is a pity. Everyone suffering from AS and other rheumatic diseases should be able to discuss their situation openly with their rheumatology health care team. The health-care team in turn should be prepared to discuss intimacy and offer advice and treatment options.

Some of the advice can address the top myths about sexuality, such as sex always equals intercourse and the goal of sex is orgasm. Another myth is that there comes a time when sex is not important. In Ms. Zink’s view, sex is as important at 80 as at 20. [See sidebar on Ms. Zink’s top 10 myths of sexuality.]

For people living with AS, it is important not to feel that their health and any physical challenges no longer make them sexy. After all, this is a young person’s disease and strikes men and women in the prime of their lives, usually before age [45]. Who wants to give up on sex and intimacy when there are decades of life left?

Key to a continuing healthy sex life is a sense of humor, proper communication, and a taste for adventure. Don’t give up!

Michael Mallinson is the president of the Canadian Spondylitis Association (CSA) and past secretary of the Ankylosing Spondylitis International Federation. He represents the CSA as a member of the Steering Committee of, and consumers as a board member of, the Arthritis Alliance of Canada. Michael is also consumer representative on the Patient Advisory Committee of the Ontario Best Practices Research Initiative, and at the Best Medicines Coalition.

“Michael Mallinson has lived with AS for more than 35 years. Michael developed this content as a consultant to Novartis Pharmaceuticals Canada Inc. No payment was received.

References:

I haven’t corresponded with SAA for a long time. However, having received the Spring 2017 issue of Spondylitis Plus, my compassion prompts a message to Charis Hill and all those who are searching for relief from pain in living life.

“I was young once, now I am old; yet I feel better now - at age 84 - than when I was 48 or even 24!”

I understand! I was young once, now I am old; yet I feel better now - at age 84 - than when I was 48 or even 24! Charis, thank you for the quote, “From the outside looking in you can never understand it. From the inside looking out you can never explain it.” I want to copy that in large calligraphy and frame it. Your descriptions about extreme fatigue, movement, annoyance, and invisibility are “right on” target. Also, when we understand that we are much more than our disease, and take our focus away from it as a detractor, we begin to heal. We all “need a spiritual retreat,” as you said.

In retrospect, as a young person, the fatigue caused a parent to chide me for being lazy. Yet, I was in God’s care, because the exercise of walking a paper delivery route in our small square mile town, before school each day, was such good therapy for something I was to learn about much later in life. There were other small signs too, even back then.

“when we understand that we are much more than our disease, and take our focus away from it as a detractor, we begin to heal.”

After marriage, I could not care for my first child for two and a half months because of sciatic pain, swollen knee joints, and restless legs. My mother took the child to my parent’s home. My husband’s mother, even though she had had strokes, took me into their home to be in bed. She faithfully put very hot, moist compresses on my legs. Very kind doctors could not find an answer for me, even at their medical conference.

After our third child was born and walking, the family doctor gave me a bottle of pills saying, “Most people feel better after taking these.” I took them as directed, one or two times a day. One day, upon seeing my little one come toward me, my thoughts and body said slurringly, “I don’t care if I don’t take care of them anymore.”

Immediately, God’s Spirit changed that thought to “I can’t take these pills.” In remembrance, I am thinking they were likely tranquilizers.

Years went on with two more precious babies, and more pain. I did my work for 30 minutes and rested for 45. Farmers and their wives worked long days. My husband, who learned to help his mother after her strokes, also helped me in the house.
“One day, upon seeing my little one come toward me, my thoughts and body said slurringly, “I don’t care if I don’t take care of them anymore.””

as well as outside. Meanwhile, no one else had a clue. I could not walk to the road for mail or to the windmill to pull the lever down to stop the wheel from turning.

At age 34, pain and red inflammation started in my left eye. I went to a specialist in Lincoln. He had a rude attitude, but the medicine - which turned the front part of my hair white, and made my tongue feel like it was covered in fur, did give relief in a bit of time. Neither that doctor nor our gentle family doctor knew the cause of my pain.

Later, our gentle family doctor retired, so there was a new one who sent me to a different eye specialist who put steroid shots between my lower eyelid and eyeball. This continued for several years. Finally, one day I told this eye specialist that I’d been sleeping in a chair at night to get some pain relief and rest for a couple of months now. He sent me to the Arthritis Clinic of Nebraska for a certain blood test: the HLA-B27 genetic test and a name for the cause of my pain was given to me. I cried in thankful relief for the knowledge. I was given several drug prescriptions, which did not work well. I continued with just high dosages of aspirin for many years.

Our kind family doctor, still interested in my case, asked me how I was doing at a community gathering, and I told him the rest of the story up to then. He looked into my eyes and said, “I am so sorry, they told us in medical school that it was a condition only men have.”

I was still in pain. I knew I wanted to keep on living, but not like that! For a while, I forced myself just to walk to get the mail each day. Then the telephone poles became new goals, one at a time. Next, I got to the corner (quarter of a mile) and after a while started doing some exercises standing, and slowly turning my body a few times. The wind pummeled me during my walks some days, which seemed like a good massage. The encouragement made me turn south and start to the next telephone pole …of course, each measure had to be retraced to get home. Self-control and persistence were needed until four miles around the section were conquered.

My husband planned trips, which he also needed, away from the demanding farm work. An Alaskan cruise brought acquaintance with a Jay and Linda from Montana who introduced to us the knowledge of a new source of help – the Spondylitis Association of America. They shared the address of SAA and I reached out. I drank in every word of their publications because it was all so familiar and someone else really knew!

I sent for their exercise videos and committed to those exercises I knew I could do. I’ve been doing them just about every morning since then. I began feeling the confidence of feeling better, though sometimes it takes a great argument with the self.
I took part in the second phase of Dr. Reveille’s research testing. I went off the heavy doses of aspirin that were destroying my digestive system. I now see a massage therapist every other week who understands, listens, encourages, and refers other patients to me, who say, “I couldn’t do that.” I tell them neither could I.

I am still tired and re-tired, but also refreshed. I do my own housework, much of the cooking, and some yard work. I take my 91-year-old husband to a community facility where we walk a half hour, six days a week. We are both cancer survivors. Creative therapy through the years includes singing at our manor, sewing for residents, repairing their clothing, sewing garments for five children and others, creating stained glass windows, and more.

Today my spiritual retreat (at 5 am this morning, with heat from the register in the corner of the kitchen) took me into God’s encouragement and learning.

Old Testament Psalm 103, Psalm 139, Psalm 46
New Testament Gospel of John 3
Philippians, especially Chapters 2 and 4 - find the strength of “to will and to do.”
Hebrews 12 and 13

God, through the giving and working in our lives wants us to know His love and compassion for each person in the world. He sends us many witnesses along the way, even and especially during adversity to make us cognizant of who He is and His gracious goodness. That is how many of the greatest hymns have been written and sung.

And now it is 7:00 a.m., time to help my husband.
Connect With Others Living With Spondylitis!

There are SAA-Sponsored Spondylitis Educational Support Groups in 21 U.S. states. IS THERE ONE NEAR YOU?

Find all of our support groups at Spondylitis.org/Groups
More ways to connect at Spondylitis.org/Community

Want to speak with someone at SAA?
Call our *Toll Free Hotline at (800) 777-8189 and speak with a real live human being Monday through Friday!

*Toll Free Hotline in U.S. only.
International members can call us at (818) 892-1616.
HELP RAISE AWARENESS with the latest spondylitis products

spondylitis.org/shop