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Fibromyalgia a Sleep Disorder

Introduction

I have lived with fibromyalgia for over 30 years. No, I don't have fibromyalgia; however, my wife certainly does. When she married a physician, she thought her health would improve. Boy was she wrong. Every year her health became worse and worse. She stated that she felt like she was 60 or 70 years old when she was only 40. I have also been blessed with a wonderful daughter who also happens to have fibromyalgia. It has been very difficult for me to witness this devastating disease first hand and see the personal struggles my wife and my daughter have had. The tremendous fatigue, total body pain, TMJ pain, irritable bowel, mental fogginess, and the discouragement of unrefreshing sleep. It seemed that no matter how long they would sleep they would wake up just as tired, if not more tired, than when they went to sleep.

I have done extensive research into this disease and have been frustrated as I am sure many of you have been in finding any kind of answer to help get your life back. Many physicians still believe that this is really not a disease, but instead, just in their head. In fact, fibromyalgia used to be called psychosomatic rheumatism. Even physicians, who understand the seriousness of this disease, are left to primarily treat this disease symptomatically. We prescribe pain medication, anti-depressants, muscle relaxants, and tell our patients to go to their local support group and learn to live with pain, fatigue, and chronic sleep problems.

No one has ever found the cause of fibromyalgia, which affects an estimated 6 to 8 million Americans and 8 out of 9 are women. It is one of the leading causes of total disability and once you have been diagnosed with fibromyalgia you quickly realize that it is a disease you must deal with the rest of your life.

After my extensive research into this disease over the past 15 years, I have come to the conclusion that the root cause of this disease is an underlying sleep disorder. We have always known that the hallmark symptom of fibromyalgia was nonrestorative sleep. In other words, you would wake up just as tired as when you went to sleep. Significant fatigue persisted throughout the day. In fact, there was a point in my wife's illness where she was unable to get out of bed for more than one or two hours a day. However, for years I always assumed that her poor sleep and fatigue was just the result of her fibromyalgia rather than the cause of her fibromyalgia.

Over the years, I have certainly been able to help thousands of fibromyalgia patients get...
their life back, including my wife and my daughter. However, I have always felt that I was missing something. I felt there was a key element in their disease I was missing that would take them to another level in their recovery. Well, now I feel that I have found that key element—disrupted sleep.

**Disrupted Sleep Disorder**

When I send my patients to a sleep lab, the main thing that the sleep physician is trying to determine is whether or not they have sleep apnea. In other words, my patients stop breathing and their blood oxygen drops dramatically placing them with a life-threatening problem. Many researchers now believe that obstructive sleep apnea is the result of underlying insulin resistance, which causes significant central weight gain and thickening of the neck. This leads to obstruction of the air flow and during sleep can cause you to stop breathing. However, as a physician, I never consider that a young, thin female patient could also have a sleep disorder. I am sure I am not alone.

In the April 10, 2003 journal of Chest a study was reported that was titled, “The Symptoms and Signs of Upper Airway Resistance Syndrome: A Link to the Functional Somatic Syndromes.” The key functional somatic syndrome they were referring to and studying was fibromyalgia. This is the official publication of the American College of Chest Physicians. I just recently became aware of this study and this article certainly opened my eyes to the possibility that this is the key to the fibromyalgia and chronic fatigue epidemic.

There are different levels of sleep. In other words, when you fall asleep, you go from a lighter sleep to a deeper sleep. Light sleep is known as alpha sleep and deeper sleep is known as delta sleep (slow wave sleep).

The deepest sleep is known as rapid eye movement or REM sleep. This is also known as dream sleep. We have known for years that fibromyalgia patients do not get into REM sleep very long, if at all. My wife recalls that she did not dream for years. However, this study and others have shown us some new and exciting aspects of sleep in patients who have been diagnosed with fibromyalgia.

Upper airway resistance syndrome (UARS) is defined as a mild obstruction to the airflow that occurs in the upper airway (nasal passageways and pharynx or throat). In a sleep study, the physician will note the smooth expansion of the chest during inspiration. However, in patients with UARS the sleep study will show blunting of this curve when you look at there upper airway pressures. Many researchers felt that this is just the early sign of obstructive sleep apnea; however, I have come to believe that it is a different problem all together.

As you fall asleep and begin to go from a lighter or alpha sleep to the deeper slow wave sleep or delta sleep, the tissues of your pharynx or throat begin to relax and decrease the size of your airway. This along with the fact that your tongue begins to also fall back into the pharynx and further close off your airway, which decreases the amount of oxygen you are getting into your lungs and consequently into your blood stream. One of the key truths I learned in medical school was the fact that the “Airway is King.” In any acute situation, the first thing you think about is being sure your patient has a good airway and that nothing is obstructing that airway. Well, I am now beginning to appreciate the fact that when you are sleeping, your airway is critical.

The above study and another study reported in the Sleep Journal (vol. 27, No. 3, 2004) titled “Inspiratory Airflow Dynamics During...
Sleep in Women with Fibromyalgia” detail what happens to patients with fibromyalgia when they finally are able to fall asleep. As these patients fall into deeper and deeper sleep, their airway closes off and they develop mild to moderate hypoxemia (low blood oxygen). Now they don’t quit breathing like you see in obstructive sleep apnea; however, they instead note that they go from deeper sleep (delta) to lighter sleep (alpha). The researchers now refer to this alpha-delta sleep. As you wake up to lighter sleep, the tissues in the throat again tighten up and the tongue moves forward, which improves your airway. You then again begin to fall into a deeper sleep and the cycle starts all over again.

This particular study looked at 28 women who had been previously diagnosed with fibromyalgia by a rheumatologist specialist. They then had them undergo a full-night polysomnography or sleep study. The prevalent sleep pattern noted in 27 of the 28 women with fibromyalgia was an inspiratory flow limitation. They also noted in these 27 women that they had an average of 30 arousals (awakenings to a lighter sleep) every hour. The quality of their sleep was significantly compromised and very little time was spent in the most important sleep level, which is REM sleep. Now not all had a significant drop in their blood oxygenation; however, sleep specialists have known for years that even a 4% drop in a patient’s blood oxygen level is significant.

These women were then placed on continuous positive pressure or CPAP for a total of three weeks with amazing results. When they looked at pain and fatigue along with other symptoms of fibromyalgia there was a 23% to 47% improvement in these functional symptoms. Let me remind you that this occurred in only three weeks on CPAP. Even with these great findings, most of the patients did not continue their CPAP because of the difficulty in using this device.

The Physiology of Sleep

Why do we need sleep at all? What is the real reason that our bodies need to sleep and rest? Well, these questions have been asked for years. All physicians realize that we do need sleep; however, the specialty of sleep medicine is just beginning to scratch the surface to these questions and the understanding of everything that goes on during sleep. There is one aspect of sleep that has always been appreciated even though you may not know all the details. We need sleep to restore the body. Restoration is therefore a key aspect of healthy, normal sleep.

Many studies have shown that one of the main hormones released during sleep is growth hormone. Growth hormone has a primary role throughout our lifetime in healing the micro tears in our muscles and other tissues. Without this normal peak activity of growth hormone during sleep, total healing does not occur. Experimental studies have taken normal individuals and interrupted their sleep via various techniques. They quickly began complaining of fatigue, muscle weakness, and mental confusion. Does this sound familiar?

Another finding with interrupted sleep is the fact that the individual has a tremendous increased production of free radicals and they develop oxidative stress. This is the primary topic of my first book, *What Your Doctor Doesn’t Know about Nutritional Medicine* [Thomas Nelson 2002]. I have had great success in placing my fibromyalgia patients on aggressive nutritional supplement program and seeing amazing and consistent improvements. My wife who had been placed on 9 prescription
medications after seeing four different medical specialists was able to get off all of her medication within weeks of starting an aggressive nutritional supplement regime. Within months, she was better than she had been in years. However, she has never been able to fully recover. She is now one of the patients I am treating with a new, more comprehensive approach.

My Clinical Approach

During this past year, I am starting my evaluation in patients who have been diagnosed with fibromyalgia with an ambulatory sleep study (Watermark ARES). This is a sleep study you can do in your home. Most sleep labs charge between $4,000 and $5,000 do a sleep study. I can do an ambulatory sleep study for around $500 and ship it anywhere in the US and Canada. Then I can review their sleep study and see if they have any sleep apnea, hypoxemia (low oxygen levels), number of arousals, upper airway resistance, and percent of time they spend in REM sleep as I am able to measure their overall sleep quality. If there is evidence of upper airway resistance, increased arousals, or hypoxemia, I recommend that they consider seeing me in my office located in Rapid City, SD. I feel that I have an excellent possibility of really being able to help my fibromyalgia patients get their life back. I am not aware of anyone in the country who is approaching this disease in the multidisciplinary fashion that I am using.

I work closely with a dentist who understands my approach in treating these patients. We fully evaluate their upper airway through ultrasound of their nasal passageway and pharynx or throat. This is called rhinometry and pharyngometry. This allows me to determine the best position to place the lower jaw to maximize the patient’s airway during sleep. If there is any evidence of nasal obstruction from a deviated septum or nasal polyps, I can evaluate this further in my office via a CT scan of the nasal passageways and upper airway. This is not done routinely; however, it is an option if there is a potential problem of obstruction that may require surgery.

Once I have fully evaluated a patient, I then recommend that they consider being fitted with a dental appliance called a mandibular advancement device (MAD). This appliance fits over the upper and lower jaw and is designed so that the lower jaw cannot slip back. Since the tongue is attached to the back of the lower jaw (mandible), the tongue will then not slip back into the throat or airway when you fall into a deeper sleep. The appliance that I am now recommending is Somnodent and an alternative is Respire. I find that my patients tolerate these appliances very well and do much better than they do with CPAP. The problem with CPAP is the fact that even though it is clinically effective, it is very difficult to use. You need to place a mask over your face along with the straps, nasal prongs, and the noise of the machine. This is why studies show that only 20% of the patients prescribed CPAP will still be using it after 6 months. A much better approach with my patients who have fibromyalgia is to prescribe this mandibular advancement device. It does take a few weeks to get used to the appliance; however, most of my patients adjust very well and after a few weeks are thrilled with the improvement they experience in their health.

My Daughter’s Story

I diagnosed my daughter, Sarah Koontz, as having fibromyalgia several years ago. She had some improvement with nutritional supplement regime I recommend for my
fibromyalgia patients; however, she never experienced the significant clinical improvement my wife had experienced. After the birth of her second child, she began having significant jaw pain and headaches. Since 50% of the patients with fibromyalgia also have TMJ joint pain, I felt that referring her to a dentist would be a good idea. However, the appliance he used to treat TMJ pain did not improve her situation. The dentist and his staff explained to her that many people who do not respond to TMJ treatment have an underlying sleep disorder, and encouraged her to consider doing a sleep study. They also shared studies with her that explained the connection between low oxygen levels during sleep, due to upper airway resistance syndrome, and clenching or grinding of the teeth as a way to open up the restricted airway. Although we were skeptical at the beginning, she asked me to start researching all the aspects of the sleep disorder seen in fibromyalgia patients, and the information was quite convincing.

We decided to do an ambulatory sleep study on Sarah, and the results proved to us that we were really on to something. Sarah’s oxygen levels averaged 85% during sleep and got as low as 77% (you never want to see oxygen levels below 90%). She also had frequent arousals and spent most of the night in a very light, unrestful sleep. For those of you who have fibromyalgia, you can understand how exciting it was for Sarah to have a medical test that actually explained the pain and fatigue she had been experiencing for years. She proceeded to be fitted for a mandibular advancement device. Our dentist used the ultrasound to challenge the collapse of her throat and also to determine the best position to place her jaw with the dental device that would keep her airway open during sleep.

Sarah was so confident that this device was going to change her life that she was able to push through the first few weeks of discomfort as her mouth adjusted to the appliance. After 2 weeks she was sleeping soundly through the night, after 4 weeks she found herself waking with the sun and full of energy. By 6 weeks she began experiencing significant improvement in her pain, and she was doing things that she never had the physical ability to do in the past.

At 3 months, we did a follow up sleep study that clinically documented the improvement Sarah has experienced since she began wearing the MAD. Her blood oxygen levels averaged 94.5% and she spent 99% of the night above 90%. Here arousals also improved significantly. Every day she is thankful for the improvement she has experienced in her health. She has expressed deep gratitude for the staff at her dentist’s office for helping her understand the condition that she suffers from, and for offering her a simple solution to the health problems that she fully expected to suffer from for the rest of her life. She is able to self-adjust her appliance for even better results and looks forward to living the life she has always desired.

Conclusion

Obviously, my daughter’s clinical result has inspired me to look into this entire connection between sleep disorder breathing and fibromyalgia. It is my conclusion that the underlying root problem in fibromyalgia is a sleep disorder that does not allow the body to go through its natural restoration process. Not only does this lead to the fatigue fibromyalgia patients experience, but also it is the cause of the total body pain, TMJ disorder, irritable bowel, and mental fogginess they also experience. Because of the tremendous free radical production that
occurs during this interrupted sleep pattern, I still recommend the aggressive nutritional supplement program I have used with great success for years in my fibromyalgia patients. However, now I feel that I can get even better clinical results with this approach. Only time will tell if I am on the right track or not.

If you are suffering from fibromyalgia/chronic fatigue and have interest in pursuing this approach, just contact me at info@raystrand.com. I can send you a report that details my approach, approximate cost, and how you can arrange to have an ambulatory sleep study done in your own home to see if you are a candidate for a mandibular advancement device (MAD). At this point in time, I must be very selective because I can only handle a few patients at a time, so please be patient with me as I pursue this exciting new approach to helping people win their battle against fibromyalgia and chronic fatigue.