

Education

I'm so tired:



arthritis and fatigue

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For many people living with arthritis, "I'm so tired" is an oft spoken phrase.

Fatigue is their constant, very unpleasant, companion. It is a symptom which is often overlooked or overshadowed by other concerns when treating arthritis, but it can be life-altering to people living with the disease.

Research into treatments for arthritis has often focussed on other disease symptoms, sometimes leaving out the importance of managing fatigue. However, some recent research has focussed on why fatigue is harmful and how it can be better treated.

"... simply feel "too tired" to do the things they want"

In an article published in Clinical Care in the Rheumatic Diseases, Basia Belza and Kori Dewing examined fatigue in arthritis and described some strategies for dealing with it and minimizing its impact.

This article cites other research to conclude that 80 – 100% of people living with certain types of inflammatory arthritis, including rheumatoid arthritis, lupus, and fibromyalgia, live with fatigue. Most types of arthritis are associated with some fatigue and it can be one of the most difficult symptoms to live with and treat.

How does fatigue affect your life?

Fatigue is definitely a social-life killer; of all things, as a young person with an active and vibrant social life, I'm often unable to participate because of the extensive fatigue I experience with my arthritis. I've missed out on birthdays, anniversaries, and just the everyday fun activities with my friends like brunch, movie nights, and playing sports.

In terms of doing household chores, I'm often left completely "zonked" by the end of it if I'm doing it on my own. Thank goodness I have friends and family to help me with such things as laundry and cleaning duties because otherwise I'd never be able to get it all done.

Fatigue also takes its toll on my body. I have to schedule my day around my fatigue levels, monitoring my fatigue, scaling activities back so as to not take up too much energy, leaving me none for the rest of the day and so forth.

I always ensure that I'll have enough sleep under my belt (minimum 10 hours) in order to be able to get my errands and school work done. The reason behind this is that if I don't get my sleep, my joints and my body ache so much more than when I'm properly rested.

Fatigue greatly impacts my personal relationship with my partner because often at night, I'm so exhausted that I'm unable to stay awake for long after my head hits that pillow. Consequently, my fatigue levels are so high that I don't feel sexy, I don't feel "up" to engaging in regular, fun, frisky sexual activity and I end up feeling guilty and badly that I'm not awake enough to share that intimacy with him.

All in all, I can easily say that whether it be when I'm with my friends, my partner, or trying to complete my work, my school, or maintain my household, fatigue greatly impacts my day to day life.

Meagan Hasek-Watt

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I'm so tired *continued*

Fatigue has been defined as “usually or always being too tired to do what you want” (Wolf et al). For people living with extreme fatigue, completing even the simplest tasks or participating in normal day to day activities can feel nearly impossible. People who face fatigue as a symptom of their disease can simply feel “too tired” to do the things they want or need to do in their lives.

Causes of fatigue

Belza and Dewing explain that there are several causes of arthritis-related fatigue, and these often occur together, including:

- **Disturbed sleep**, often caused by the pain associated with arthritis. This can lead to daytime tiredness.
- **Inactivity**, often due to the pain and swelling in joints and tissue associated with arthritis. This can lead to loss of strength and muscle tone, making daily tasks more difficult.

- **Pain**, which can cause people to use up more energy to complete simple tasks, leading to fatigue.
- **Medications**, taken to control arthritis can cause fatigue; in fact, most arthritis medications list fatigue as a potential side-effect.

Managing fatigue

It can feel impossible to take on anything else in your life when you are tired; yet there are some steps that you can take to reduce your fatigue and find a brighter, more energetic you. It might seem difficult, but including some or all of these strategies in your arthritis treatment plan could pay off by lessening your fatigue:

- **Cardiovascular exercise:** Studies have shown that aerobic training increases endurance, allowing you to do more and use up less energy.
- **Strength training:** The more you increase

your muscle mass, the less energy you will need to expend as you go through your day.

- **Monitor your energy and fatigue levels:** Understand that you may have a finite amount of energy in your day, and be aware of how much energy you are expending on the tasks you need to complete. Take rest breaks and try to avoid “overdoing it”.
- **Ergonomics:** Make sure you are using proper postures, equipment positioning, and tools. When in pain, or suffering from inflamed joints, people often use up more energy than they need to. Using adaptive tools in the kitchen and around the house, and making sure workstations are designed with the proper height of desk and chair, are examples of how you can reduce wasted energy.
- **Practice good “sleep hygiene”:** For some ideas about how to sleep better, read our “Tips for better sleep” article below. <

Tips for better sleep

Common sense tells us that getting enough sleep is one key way to minimize fatigue. But getting to sleep — and staying that way — can be very difficult, especially for people who live with arthritis. Here is a list of some of the things you can do to help you sleep better.

- Keep a regular sleep-wake pattern. Try to go to bed at the same time each night, and wake up around the same time each morning.
- Avoid alcohol and caffeine in the late afternoon and evening. Though alcohol can make you sleepy, it can disrupt sleep as well.
- If you need to nap during the day, keep it short; under an hour is best.
- Keep your bedroom only for sleeping—avoid activities like watching television, eating, and working on your computer in your bedroom.
- Exercise regularly, but avoid doing so for at least three hours before bed. Exercise can be stimulating, as opposed to relaxing.
- Keep your bedroom cool and dark.
- Fresh air is important; if possible, sleep with a window slightly open.
- Take time to relax before bed. Take a warm bath, listen to soothing music, drink chamomile tea, read a relaxing book.

- Make sure your mattress and pillows are of a firmness comfortable to you. Experiment with pillow type and positioning to find a set-up which works for you. Look into the many different types of pillows on the market, including wedge-shaped pillows and body pillows.
- Control your pain at night time. Talk to your doctor about adjusting your pain medication schedule so that your pain is relieved at night. <



Spotlight on Sjogren's syndrome

This month's spotlight on Sjogren's syndrome is coming to you because of a reader request. We are thrilled to be able to present information requested by our readers, and are excited to be receiving requests from readers for spotlight features on different types of arthritis. Please contact us at info@arthritisconsumerexperts.org if you would like us to profile a specific type of arthritis.

Sjogren's syndrome is an inflammatory autoimmune disease (like arthritis) in which white blood cells—the body's immune system—attack moisture-producing glands. Most often, this results in dry eyes and mouth, although it can also affect joints and muscles, as well as organs including the liver, pancreas, kidneys, lungs, stomach, and brain.

Sjogren's syndrome affects women much more commonly than men—90% of those diagnosed are women. Though it can occur in people of all ages, it tends to strike around middle age; most commonly, people are diagnosed between the ages of 45 and 55.

Approximately half of those diagnosed with Sjogren's syndrome also have another form of arthritis, like lupus, scleroderma, or rheumatoid arthritis—this is called "secondary Sjogren's syndrome". In the other half of cases, Sjogren's syndrome appears in people with no other history of arthritis—in this case, the disease is referred to as "primary Sjogren's syndrome".

The cause of Sjogren's syndrome remains unknown, although scientists think that it may be the result of a virus or environmental trigger. Because the disease most often affects women at the end of their childbearing years, it has also been speculated that it may have a hormonal connection. Since Sjogren's syndrome is an autoimmune disorder, many researchers believe that a combination of these and other factors causes something to go wrong with the immune system, causing the body to attack its own healthy glands and organs.

Diagnosis of Sjogren's syndrome

Sjogren's syndrome has several warning signs,

which may be present at the onset of disease. These include:

- Very dry, "gritty" feeling eyes
- Dry mouth, sometimes making swallowing difficult
- Dry nose and throat
- Swollen salivary glands
- Fatigue
- Joint pain, swelling, and stiffness, most often in smaller joints like fingers and toes.
- Occasionally lung, kidney and other organs can be affected by Sjogren's syndrome

The most common early symptoms of Sjogren's syndrome are dry eyes and mouth, which can make it a challenging disease to diagnose as other conditions, like hormonal disorders, can often present these symptoms as well. Dry mouth and eyes can also be associated with aging, menopause, and certain medications. As well, Sjogren's syndrome is not a particularly well-known disease, and may be overlooked by some doctors. If you think you might have Sjogren's syndrome, speak with your doctor about your symptoms.

If your doctor believes you may have Sjogren's syndrome, you will usually be referred to a rheumatologist—a specialist in the treatment of arthritis. Rheumatologists have many years of extra training on top of their regular medical schooling, and are experts at diagnosing and treating all forms of arthritis, including Sjogren's syndrome. If your eyes appear to be involved in your disease, you may also be referred to an ophthalmologist—a medical doctor specializing in eyes.

To get a firm diagnosis of Sjogren's syndrome doctors may run a number of tests. These may include urine and blood tests, lip biopsy, X-ray imaging, and a special test (called a Schirmer tear test) which measures dryness in the eyes.

People with primary Sjogren's syndrome sometimes develop blood, lung or kidney problems. They are also at a higher risk for a lymph node cancer called lymphoma. Regular follow up with their physicians to monitor for kidney and lung disease as well as lymph node check ups are important.

Treatment of Sjogren's syndrome

Once your rheumatologist has diagnosed Sjogren's syndrome, there are effective treatments available to help you manage the symptoms. While there is no known cure for Sjogren's syndrome, treatments are available, and your rheumatologist is the best person to discuss these with and formulate a treatment plan.

There are several groups of medications used to treat Sjogren's syndrome. These are:

- **Non-steroidal anti-inflammatory drugs (NSAIDs)**, such as ibuprofen (for example Advil® or Motrin IB®), naproxen (or Naprosyn®), diclofenac (or Voltaren® and Arthrotec®)
- **Corticosteroids**, such as prednisone
- **Disease-modifying anti-rheumatic drugs (DMARDs)** such as methotrexate, sulfasalazine, hydroxychloroquine and azathioprine

These medications can work alone, or most often, in combination to reduce the pain and other symptoms associated with Sjogren's syndrome, and other disorders associated with secondary Sjogren's syndrome.

There are a number of strategies to treat the dryness of the eyes and mouth often associated with Sjogren's syndrome. To care for dry eyes, artificial tears may help to reduce dryness and increase comfort. To ease a dry mouth, try sipping water frequently throughout the day, chewing sugarless gum, and avoiding foods which can be drying to the mouth, such as chocolate and nuts. Mouthwashes and sprays are also available to help maintain moisture in the mouth. It is important to avoid medications that can cause a dry mouth, if possible.

Saliva is important to keep the teeth and gums healthy. People with Sjogren's syndrome have a much higher chance of developing tooth and gum disease. It is important to follow up regularly with a dentist to maintain oral health.

Keeping skin from getting too dry is important. Try using creams or mineral oils to protect skin and keep it from becoming uncomfortable and dry. Using a humidifier in your home may help prevent dry skin and keep mucous membranes moist. Avoid air conditioners and electric heaters wherever possible.

As with any form of arthritis, maintaining a healthy lifestyle is also a critical part of any Sjogren's syndrome treatment plan. Poor diet, lack of exercise, and high levels of stress may make disease activity worse, so healthy eating, appropriate levels of aerobic and strengthening exercise, and relaxation are highly recommended. As well, since smoking can cause dryness in the skin, mouth, nose, and eyes, it is highly recommended that people with Sjogren's syndrome do not smoke. ◀

Arthritis Consumer Experts

Who we are

Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower people living with all forms of arthritis to take control of their disease and to take action in health care and research decision making. ACE activities are guided by its members and led by people with arthritis, leading medical professionals and the ACE Advisory Board. To learn more about ACE, visit

www.arthritisconsumerexperts.org

Guiding principles and acknowledgement

Guiding Principles

Health care is a human right. Those in health care, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the

influence of any specific constituency and a practical necessity. Any profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.
- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and health care providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- ACE does not promote any "brand", product or program on any of its materials or its web site, or during any of its educational programs or activities.

Thanks

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Disclaimer

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