

A young woman with her hair in a bun, wearing a white knitted sweater, is shown from the chest up. She has her eyes closed and is resting her head on her right hand, appearing to be tired or stressed. The background is a soft, out-of-focus blue with some light spots.

# 15 TYPES OF SJÖGREN'S FATIGUE

By Teri Rumpf, Ph.D.



The 15 types of fatigue result from the 2nd revival of an essay Teri Rumpf wrote for the Sjögren's Foundation ([www.sjogrens.org](http://www.sjogrens.org)) almost 2 decades ago, originally entitled 11 Types of Fatigue.

Fatigue is one of the most prevalent and disabling patient reported symptom of Sjögren's. Fatigue in Sjögren's clearly differs from ordinary tiredness. We describe it as an ever-present, fluctuating, and nonrelievable lack of vitality being beyond one's own control. Not everyone experiences it in the same way, but fatigue is undeniably a permanent part of patients' lives. It is a debilitating symptom which is associated with reduced health-related quality of life.

Because we want to contribute to increase awareness and acknowledgment of fatigue as a major factor in Sjögren's and promote a growing knowledge that Sjögren's is a systemic disease, we share Teri Rumpf's 15 different fatigue subtypes. With this we hope to highlight a topic often misinterpreted and so poorly addressed.

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It's difficult to explain the unnatural quality and intensity of Sjögren's fatigue to someone whose only experience has been with what is normal. We're not talking about the same stuff. It's apples and artichokes. Sjögren's fatigue assaults everything I do. There isn't a part of my life that hasn't been touched by it. It is there even on my happiest days.

Because people don't understand, it's often misinterpreted. "Is it depression?" a health care professional who didn't know much about Sjögren's asked me. I tensed. Was he saying it was all in my head? I began to get angry but then gave him the benefit of the doubt. I put my first reaction aside and decided he was trying to understand. I was relating something outside his frame of reference, and he was attempting to find a point with which he could identify.

When you describe Sjögren's fatigue to someone who has never experienced it, you are asking him or her to think outside the box. You want them to understand an experience that is common to those who have Sjögren's and many other autoimmune diseases but rare otherwise. Perhaps their first reaction will be negation or denial. While it's always difficult to encounter expressions of disbelief, it is not uncommon. I tried to see it as an opportunity to educate.

"No," I said to the doctor who asked about depression, "think of it as a never-ending flu that varies in intensity but never goes away." He grimaced.

1

## Basic fatigue

is a continuous presence for many Sjögren's sufferers.

This is the inherent fatigue that I attribute to the inflammatory, autoimmune nature of Sjögren's. It's with me all the time. It differs from normal fatigue in that you don't have to do anything to deserve it. It can vary from day to day but is always there. For me, there appears to be a correlation between this kind of fatigue and sed rate (ESR). When one goes up, so does the other.

I don't know how often this phenomenon occurs. I could also call this my baseline fatigue, which fluctuates and gets better or worse. All of the following are superimposed on this basic fatigue.



2

## Rebound fatigue

is a reminder that I have done too much.

If I push myself too far and ignore the cues my body is sending me to stop and rest, my body will fight back. When I do more than I should, the result is an immobilizing fatigue.

It comes on after the fact, i.e., do too much one day and feel it the next. If I push myself today, I very likely will have to cancel everything tomorrow. An extended period of doing more than I should will almost certainly cause a flare.



3

## Sudden fatigue

can hit you anywhere, at any time.

This 'crumple and fold' phenomenon makes me resemble a piece of laundry. It comes on suddenly, and I have to stop whatever I'm doing and just sit down (as soon as I can). It can happen anywhere, at any time.

It is the kind of fatigue that makes me shut off the computer in mid-sentence. It is visible to those who are observant and know what to look for, even though I make gargantuan efforts to disguise the fact that it is happening.



4

## Weather-related fatigue

is a side effect of forecasting changes in the weather.

Not everyone has this particular talent, but I can tell that the barometric pressure is dropping while the sky remains blue and cloudless. I feel a sweeping wave, a malaise, that sometimes lifts just after the rain or snow has started.

Likewise, I know when a weather front is moving away, even while torrents of water are falling from the sky. I feel a lightening in my body and begin to have more energy. This kind of fatigue is accompanied by an increase in muscle aches and joint pain.



5

## Molten Lead phenomenon

is a predictor of a really bad day.

This fatigue is present when I open my eyes in the morning and know that it is going to be a particularly bad day. It feels as if someone has poured molten lead in my head and on all my limbs while I slept.

My muscles and joints hurt and doing anything is like walking with heavy weights. It is often associated with increased symptoms of fibromyalgia and sometimes helped by heat and massage.



6

## Tired-wired

when you are physically exhausted  
but your mind is still whirling.

Tired-wired is a feeling that comes from certain medications, such as prednisone, too much caffeine, or too much excitement or perhaps it is just a function of Sjögren's. My body is tired, but my mind wants to keep going and won't let my body rest.

7

## Flare-related fatigue

Unpredictable, can last for days or weeks.

Flare-related fatigue is an unpredictable state of increased fatigue that can last for days or weeks. It may be caused by an increase in disease activity or an undetected infection. If the latter, it either resolves on its own, or eventually presents other signs and symptoms that can be diagnosed.

Additional rest is essential to deal with this kind of fatigue, but rest alone will not necessarily improve it or make it go away. Once a flare begins, it is impossible to predict where it will go or how long it will last.



8

## Fatigue related to other physical causes

feels like climbing up a steep hill when you are walking on flat ground.

Fatigue related to other physical causes, such as thyroid problems or anemia or other diseases superimposed on Sjögren's. This kind of fatigue makes you feel that you are climbing a steep hill when you are really walking on level ground. It may resolve once the underlying organic condition is diagnosed and treated.

Thyroid problems and anemia are both common among Sjögren's patients, but many other kinds of fatigue may be superimposed. Sjögren's and fibromyalgia often co-exist, such that it is difficult to separate one from the other.



9

## Fatigue impairs concentration

encloses me in a thick cloud of cotton wool.

Fatigue impairs concentration, precludes thought, and makes me too tired to talk, think or read. Fatigue robs me of memory and encloses me in a fog of cotton wool so thick I can't find my way out until the fog miraculously lifts.

For me, brain fog goes hand-in-hand with other kinds of pernicious fatigue.

10

## Stress, distress, anxiety or depression

create emotional fatigue that can be as exhausting as physical fatigue.

Stress, distress, anxiety or depression all can create a leaden kind of emotional fatigue that can be as exhausting as one due to physical causes.

Although some people do not associate their increased fatigue with emotional states, many are aware of the effects of increased anxiety and depression, even if they cannot control what they feel. Intense emotion is very draining. Stress, anxiety and depression all are known to disrupt sleep.



11

### Fatigue that comes from not sleeping well

getting to sleep and staying asleep can be a challenge for Sjögren's sufferers.

Some people with Sjögren have trouble both getting to sleep and staying asleep. Some wake up in the morning feeling as if they had never slept at all. Many aspects of Sjögren's affect sleep: being too dry, in too much pain or malaise; multiple trips to the bathroom, the need for water or to put in eye ointment all deter a good sleep.

Lack of restorative sleep increases fatigue. Fibromyalgia worsens when you don't get a good night's sleep. Chronic pain increases fatigue.

12

## Fatigue that comes with normal ageing

it still hurts that I cannot keep up with friends of the same age.

I'm old enough for Medicare now and my friends are more tired too, although they seem to be able to do two or three or even four times what I can do on any given day.

In fact, the gap between what they can do and what I can do just seems to be growing, despite my best efforts. It's been a long time since I tried to keep up, but it still hurts that I can't.

13

### Fatigue that comes from a chronic illness that just won't quit

it is easy to be "sick and tired of being sick and tired" when Sjögren's just does not go away.

We've all heard the expression "sick and tired of being sick and tired" and that phrase truly captures what many of us feel. I would take it one step further. There's a fatigue that comes with the uncertainty of a chronic disease. It's a debilitating fatigue born of never knowing what will come next.

The chronicity of Sjögren can wear me down and I have to make special attempts not to let it. When these attempts don't work, I wait a while and try to find something else that distracts me from my illness.

14

Fatigue that comes from trying to keep up with family and friends who don't have a chronic illness

my body won't co-operate and I can't keep up.

As much as I try, it just isn't possible to keep up. I'm on a schedule that's all my own, and as much as I fight it, it separates me from the people I love.

I'm willing to compromise to do things their way, but my body won't cooperate.

15

## Doctor fatigue

repeated clinical visits and tests are exhausting.

I get very tired of spending my time in waiting rooms, having lab tests, and going to doctors.

I don't understand why I didn't say this before. I'm sure it's self-explanatory.

Enough said.



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