

## **The American Perspective: ITP and Fatigue**

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Many of my ITP patients report that they are tired all the time. That they barely have the energy to make it through the day. That they feel exhausted, even when they first wake up in the morning after a full night's sleep. That they choose to opt out of social and recreational activities because they just don't have the energy. Some of them even tell me that fatigue is the worst part of their ITP, worse than the low platelet counts or bleeding symptoms.

If my patients' concerns resonate with you, you may have ITP-associated fatigue. My goal in this edition of *The American Perspective* is to address common questions about ITP-associated fatigue including what it is, how common it is, what causes it, and how it can be treated.

### **What is fatigue?**

The colloquial definition of fatigue, according to the *Oxford English Dictionary*, is a feeling of being extremely tired, usually because of hard work or exercise. We all know the feeling of fatigue in this sense -- it's the tiredness we feel after a long day's work.

When we talk about ITP-associated fatigue, we are not referring to the colloquial definition. Rather, we are talking about medical fatigue. The medical definition of fatigue is different from the colloquial definition in two respects. First, medical fatigue is so severe that it interferes with an individual's ability to function and enjoy a normal quality of life. Second, medical fatigue occurs in the absence of hard work

or exercise. We all know this feeling too -- it is the total lack of energy we feel when we're sick, for example when we're home with the flu.

### **How common is fatigue in individuals with ITP?**

Research studies indicate that about 40-50% of ITP patients suffer from fatigue. Fatigue is much more common in individuals with ITP than in the general population. High rates of fatigue in ITP have been reported in adults and children, and in studies all over the world, from the UK and Europe to the US and Canada to India and Japan. In the ITP World Impact Survey, a large study involving more than 1500 patients from 13 countries, 50% of respondents reported fatigue and 65% of these individuals classified their fatigue as severe. Remarkably, fatigue was the most common symptom reported, more common than bruising, petechiae, anxiety around unstable platelet counts, or any of the other 11 symptoms queried in the survey.

### **What causes ITP-associated fatigue?**

There are multiple potential causes of fatigue in patients with ITP and causes may differ among patients. Some patients may have more than one reason for their fatigue.

Inflammation leading to something called "sickness behavior" is probably a major contributor to ITP-associated fatigue in many patients. When we get the flu, our bodies become inflamed. Inflammatory chemicals called cytokines cause us to feel fatigued. In the context of the flu, the fatigue serves a purpose. It encourages us to stay in bed, rest, and reserve our energy for fighting off the infection. This tendency to stay in bed when we have the flu is called "sickness behavior". Some patients with ITP also have "sickness behavior" due to increased inflammation and elevated cytokines. But unlike the flu, which

usually goes away after a few days of rest, ITP is longer-lasting and patients must learn to cope with their fatigue as they navigate their daily lives.

All sorts of other factors may also contribute to ITP-associated fatigue. Some patients with ITP have other illnesses that cause fatigue (for example, underactive thyroid or depression). Medications used to treat ITP such as steroids may cause fatigue or interfere with sleep. The stress of having a disease like ITP, itself, can be fatiguing. Bleeding due to low platelets (for example, heavy menstrual periods) can cause iron-deficiency, which is associated with fatigue. Some patients with ITP reduce physical activity for fear of bleeding, which can lead to deconditioning and decreased energy.

### **What can be done to treat fatigue?**

There are many treatment strategies available for improving fatigue. In general, treatment of fatigue should target the cause(s) of fatigue in an individual patient. If you feel that you are experiencing fatigue, be sure to mention it to your physician. Your physician will need to perform testing to identify what is causing your fatigue. For example, if you are found to have an underactive thyroid, you will need treatment with thyroid hormone replacement. If you have iron-deficiency, you will need iron supplementation. If steroids are disrupting your sleep, you and your doctor should seek an alternative to steroids. You should get regular exercise and practice good sleep hygiene. In some cases, a sleep aid such as melatonin may be warranted. If anxiety or depression are interfering with your sleep, you may benefit from counseling and/or medical therapy.

Some ITP patients report that fatigue tracks with their platelet count. They are most fatigued when their platelet count is low and they experience an energy boost when their platelet count goes up. Make your

physician aware of whether you feel better when your platelet count is higher. You and your physician can use this information to develop treatment goals that help you feel your best.