



Fatigue in ITP

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The information in this booklet is intended to offer helpful suggestions, and should not replace advice given by your doctor.

We are most grateful to Prof. James N. Goerge for reviewing and approving the content of this booklet.

Introduction

by Professor James N. George & Professor George R. Buchanan

We've learned from our patients with ITP that many of them have symptoms of fatigue. When we've asked people attending the annual ITP Support Association Convention if they are bothered by fatigue, almost everyone raises their hand. Fatigue has been documented in focus groups of patients with ITP; in these groups, over 90% of patients have described symptoms of fatigue. Many patients say that their symptoms of fatigue are worse when their platelet count is low. But in spite of all of these experiences, doctors caring for patients with ITP commonly dismiss symptoms of fatigue as unimportant. This contrast, between what patients describe and what doctors believe, is an important problem for the care of ITP patients. It is a problem that the ITP Support Association is committed to solve.

There are several reasons why doctors do not believe that fatigue is an important problem for patients with ITP. First, doctors don't understand why fatigue may occur. ITP is a disorder apparently limited to blood platelets, and the only well known function of blood platelets is to prevent bleeding. Therefore bleeding and bruising symptoms are the only problems that doctors are concerned about as they care for ITP patients. Second, fatigue is something everyone has sometime. The doctor herself may feel fatigued as she listens to an ITP patient describing fatigue, and therefore she may think this is unrelated to ITP. Third, even if the doctor accepted that a patient's fatigue was a real problem that is really associated with the ITP, she may not know what to do about it. Finally, there have been no objective data to convince doctors that fatigue is actually a problem associated with ITP. There has been no study of a large number of ITP patients that used standardized and validated questions to determine the actual frequency of fatigue among ITP patients. Until now.

The ITP Support Association began its effort to correct this problem with the presentation of Dr. Julia Newton of Newcastle at the 2009 Convention in Edinburgh. Dr. Newton is a physician who specializes in understanding the causes and determining effective treatment of fatigue in many different diseases – but not ITP. She learned a lot about ITP at the Convention and she has become the leader of the Support Association's effort. With the help of

Shirley Watson, Dr. Newton created a comprehensive survey to define fatigue in adult patients with ITP. One year ago, the Support Association distributed these surveys about fatigue to all 1871 of its members; 31% responded. We sent the same survey to the 93 patients enrolled in the Oklahoma ITP Registry; 74% responded. The survey contained specific and standardized questions about fatigue that have been used in previous studies of patients with multiple different diseases as well as healthy people.

The results of the survey are remarkable. First, most patients reported significant fatigue, whether or not their ITP was currently active. (We defined patients as having “active ITP” if their platelet count was low and/or they were currently taking treatment for ITP.) The frequency of fatigue was greater in patients with active ITP than among patients whose ITP was in remission. 43% of the 386 patients who had active ITP had significant fatigue, determined by their responses to these questions; 28% of the 226 patients with ITP in remission also had significant fatigue. These are both greater than the expected 2.5% frequency of fatigue in healthy people. The presence of fatigue was not different between the UK and US patient groups. Other parts of the questionnaire asked about symptoms of dizziness (for example, feeling dizzy when you first stand up or remain standing for a long time) and symptoms of daytime sleepiness. These problems were related to the frequency of fatigue and may provide clues as to the cause of fatigue in patients with ITP and its possible treatment. Another important result of this survey was the things that were not related to fatigue. The presence of fatigue was not related to how old our patients are, whether they were men or women, how long they have had ITP, and whether or not they have had a splenectomy.

The most important conclusion is that the ITP Support Association’s survey confirmed that fatigue is an important problem among patients with ITP. This may not be news for patients with ITP, but it is important news for their doctors. Based on these data, doctors may now believe that the symptoms of fatigue in patients with ITP are real, and they may now believe that fatigue is a real part of ITP. Based on Dr. Newton’s experience with studies of fatigue in other diseases, there may be other tests that can help us to determine what may be causing the fatigue in ITP patients and how it may be treated. These studies by the ITP Support Association will help to improve the lives of our patients.

FATIGUE IN ITP

THE HIDDEN SYMPTOM

Fatigue is a common complaint

Tiredness is one of the commonest reasons for someone to see their GP, yet in over 90% of these patients no explanation can be found. Extreme tiredness that is present most or all of the time is usually referred to as fatigue. If this is a long term condition it will be called chronic fatigue, as in medical terminology chronic relates to length of time rather than severity. This sort of fatigue can be overwhelming and is often not relieved by sleep. Although physical and mental fatigue are different they often exist together. With physical fatigue a person cannot carry out their normal level of functions, whereas mental fatigue causes lack of concentration and the need to sleep.

Doctors describe what the patients feels, such as a headache or tiredness, as a symptom, whereas something the doctor can see, for example a rash, is often called a sign. Fatigue is a recognised symptom in various conditions including cancer, heart disease, ME (chronic fatigue syndrome), coeliac disease, iron deficient anaemia, diabetes, depression glandular fever and many other conditions. It can also be caused by treatments such as radiotherapy, chemotherapy, antihistamines, steroids and statins. Fatigue is present in many autoimmune conditions but less well recognised, possibly because there is no physical evidence to explain it and no easy way to measure it. Excessive anxiety, stress and family problems can also be triggers for fatigue. So if you suffer from fatigue, albeit related to ITP, you are not alone!

Fatigue is now recognised as a common symptom of ITP and research shows that Interleukin (IL)-6, a pro-inflammatory protein related to fatigue, is elevated in people with ITP. Nevertheless, doctors should check that ITP patients with severe fatigue do not have other causes such as low iron, thyroid function problems or depression.

Are you getting a good night's sleep?

Although some people suffering fatigue have difficulty staying awake during the day, others can find themselves frustrated by an inability to sleep and get the rest they so badly need.

Top tips for a better night's sleep include:-

- Go to bed and get up at a regular time, and try to follow the same bedtime routine
- Mental and physical exercise during the day, particularly late afternoon or evening, will help you sleep at night.
- Take a short nap after lunch if it helps you stay awake in the evening and doesn't interfere with your sleep at night.
- Avoid dozing in front of the TV during the evening by doing some other light activity such as playing cards, reading, ironing, sending texts to friends, etc and regularly moving out of your chair.
- Keep the bedroom dark, and use blackout blinds or an eye-mask if necessary. If you (or your partner) are likely to need the loo in the night a very low wattage plug with a bulb that gives an orange or red glow to light your way is less wakeful than turning the main light on.
- Try to keep night time noise levels low in your household, or if that is impossible wear earplugs. A radio turned on very softly can help to muffle sudden sounds and relieve the boredom of insomnia, but avoid turning on the television which flashes even on radio mode.
- Make sure your bedroom is not too hot, but warm enough to avoid heavy bedding. Some people find duvets unbearably hot even in the lowest temperatures while others like to bask in the heat of an electric blanket, so experiment with your bed covers and room temperature until you find what works for you.
- It can help to have a light bedtime snack, and many people find a warm milky non-caffeine drink relaxing. Avoid alcohol which tends to initially induce

sleep but causes wakefulness later in the night.

- Try reading or doing a puzzle before settling down and if you can't get to sleep try mental relaxation exercises such as recalling the names of all the people you know in your road, remembering what is sold in each aisle of your supermarket, or imagining yourself laying on a warm beach listening to the sea and sounds around you.
- Keep calm and don't let yourself get angry that you can't sleep. Try not to get up and make a drink as it will wake you more. Have a glass of water or juice by your bedside, or if you prefer a warm drink, take one in a flask when you go to bed.
- If sleep still fails you, listen to some gentle music, relaxation CD or audio books and let your body relax and rest.

Eat healthily

There are no foods or diet known to counteract fatigue or raise platelet counts in ITP. However, University Health News, which reports information emanating from some of America's most respected medical schools, hospitals and health centres states that the developed world is becoming overfed and undernourished, and many people are fatigued because they are not getting enough vitamin B, magnesium or anti-oxidants.* Eating a good balanced diet gives your body the best chance to fight fatigue. It may be tempting to pick at snacks rather than cook a meal, but it is important to eat a healthy balance of protein, carbohydrates, fresh fruit and vegetables. If your appetite is poor it is important that the food you do eat is of good nutritional quality. In our factsheet "Healthy Eating and ITP" registered dietician Sue Wood recommends that the best way to ensure a good diet is to choose foods from each of the 5 food groups:

- Plenty of fruit and vegetables – at least 5 a day
- Plenty of bread, rice, potatoes, pasta and other starchy foods – choose wholegrain varieties whenever you can
- Some milk and dairy foods – choose mostly lower fat versions.

* <https://universityhealthnews.com/daily/energy/3-top-nutritional-deficiencies-as-fatigue-causes/>

- Some lean meat, fish, eggs, beans, nuts and seeds – cook without added fat
- Just a small amount of foods and drinks high in fat and/or sugar.

Top tips to eat healthily when suffering fatigue include:

- Buy and cook food that needs little preparation. For example, tipping some cubes of meat, tin of kidney beans, a pack of diced vegetables and a can of tasty soup or cook-in sauce into a slow cooker gives a nutritious meal with so little effort - even a child could manage it. If you have a computer there are plenty of websites giving healthy recipes that require little preparation Encourage your family (including the children) to help with preparation or to take turns in cooking. Don't pamper to fussy eaters, if someone wants something different to the rest, let them cook it!
- If you have fluctuating energy levels prepare double quantity meals on the good days and freeze ready to thaw and eat on the bad days.
- Being overweight increases fatigue, so it is important not to snack and or to overdo the carbohydrates, particularly sugar. If you are hungry between meals eat fruit or vegetable sticks.
- Some people feel better eating smaller more frequent meals. Providing these are not sugary snacks this can help stabilise your blood sugar levels.
- If using ready made meals, look for those with lower fat, salt and sugar levels.
- Superfoods are a media myth and the EU has banned the word from food packaging unless supporting evidence exists!
- Vitamin and mineral supplements are fine at recommended doses, but don't overdose as this can be harmful or cause side effects.
- Supplements that purport to boost the immune system are not recommended in ITP patients (or anyone with an autoimmune disease).
- Drink plenty of fluids, but limit the number of drinks with added sugar or high natural sugar content.

- The Royal College of Psychiatrists recommends cutting out caffeine for a month to see if that helps relieve fatigue.
- The NHS Choices website gives advice on an Energy Diet to combat fatigue at www.nhs.uk/Livewell/tiredness-and-fatigue/Pages/energy-diet.aspx

It's true, exercise can help!

Although fatigue can make it extremely difficult to find any motivation to start exercising, studies show that it really does boost energy levels. It improves the physical efficiency of your heart, circulatory system, lungs and muscles, and is good for the brain. It also aids flexibility and helps prevent obesity.

Regular light exercise is proven to be beneficial in combatting fatigue.

- Start with short walks (even if only around the house or garden), a few floor exercises, or low level work out on the WiFi.
- Start very gently and build up your routine gradually.
- Exercising with others can be more enjoyable and help you to stick at the routine. Try yoga, tai chi or gentle exercise classes
- If you feel unable to exercise or it makes you feel worse ask your consultant if you can see a physiotherapist or occupational therapist for advice.

Reducing stress

It can be difficult to avoid stress but reducing stress has been shown to boost energy. Try to add some relaxation techniques into your day – listen to calming music, have a warm bath, read books and magazines, do puzzles, watch a comedy programme, have a laugh with friends, or enrol for some relaxation classes

Fatigue and your family

Your fatigue can also put a strain on the rest of the family as they try to cover chores normally done by you – perhaps not done so easily or so well by them! Do

talk about the problems together so that resentment and guilt doesn't build up. Perhaps another relative might be able to help, or some chores could be done less often or abandoned. Your partner may feel worried and inadequate because they don't know how to help you feel better, and they too may need to talk with someone outside the immediate family. It is important to remember fatigue is not your fault, just a horrible symptom of ITP!

Managing at home

What was once your normal routine at home can become an unbearable burden when fatigue gets a grip. If you find yourself unable to cope with the chores and family commitments try to prioritise what is really important, and don't feel guilty if other things slide. Keep positive and try not to let any feelings of frustration and failure take hold.

Top tips for managing at home:-

- Pace yourself. Be realistic and aim for too little rather than too much so you enjoy a feeling of achievement rather than failure.
- Spread chores over the week (or two weeks) and plan your day, doing the most important or most taxing activity first.
- Try to maintain contact with family and friends and share your feelings with them. Fatigue is not immediately visible like a broken leg, and if those close to you don't understand how you feel they may not realise you need sympathy and support.
- Don't refuse offers of help!
- If shopping is too strenuous use supermarket deliveries and internet shopping when you can.
- Some people find that complementary therapies such as aromatherapy, reflexology, reiki and massage can help them to feel more in control.

Managing at work

Some people find it a real problem to continue working when they are struggling with fatigue. With low energy levels it can take more time to get ready

in the morning and travelling to the workplace can feel like a huge physical effort. Then somehow you have to cope with the rigours of the working day. Many people are afraid to tell their employer and colleagues as they fear being overlooked in the next promotion round.

However, if you talk to your employer or human resources department they cannot discriminate against you because you are unwell. If you are unsure of gaining their sympathy, ask your consultant for a note confirming that you have ITP and are suffering from chronic fatigue, or take in a copy of this booklet

Top tips for managing at work:-

- If you find it difficult to get in on time, or find rush hour too stressful ask if you can change your start and finishing times. Your employer may allow you to work flexi-time although this will depend on your job and whether you are needed to cover a task for specific hours.
- Explaining your fatigue to your colleagues may be difficult, but it will help them to understand and support you.
- Ask if you can swap jobs or have lighter work if your job is physically too tiring.
- Cat nap in the rest room or in your car after you eat at lunch time - use an alarm if you are worried about oversleeping. Ten minutes sleep followed by a cup of coffee can work wonders according to the American Academy of sleep.
- If you usually drive into work see if you can find someone to give you a lift or share the driving.
- If you have a suitable job, ask if you can do some work from home if it will help you to pace yourself.
- If you are not also suffering from insomnia, aim to go to bed earlier to get a longer night's sleep.

Support is available

People can feel very isolated with their fatigue, and sometimes avoid talking about it to their partner as they don't want to worry them. If you can't share your

feelings with a partner, close family member or friend, it may help to talk about your fatigue problems with others outside your immediate circle:-

- Join one of the ITP Social Networks
- Talk to a counsellor (your GP or the Citizen's Advice Bureau can tell you about appropriate counsellors in your area)
- Talk to a religious leader or spiritual advisor (of any faith)
- Phone or email one or all of the three ITP Support Association nominated 'Patient Mentors' (members only service – contact details are in The Platelet).

Talk to your consultant

Tell your haematologist about your fatigue. You wouldn't be hesitant to mention nosebleeds or bruising, so there is no reason not to discuss your level of fatigue. It may help to take a close relative or friend with you for moral support when explaining how fatigue is affecting your life. If the consultant informs you that fatigue is not a symptom of ITP show them this booklet or refer them to the paper *Fatigue in Immune Thrombocytopenia** published in Mar 2015 in the British Medical Journal by leading ITP specialists Dr Quentin Hill and Prof. Adrian Newland . Should he/she continue to be unsympathetic or deny it is a common symptom of ITP you have the option to ask for a referral on the NHS to a more experienced ITP consultant (such as at one of the ITP Clinical Centres listed at www.itpsupport.org.uk/itpforum/centres.htm.) You can be referred by your hospital consultant or GP.

Your consultant may wish to check that there is no other cause for your fatigue such as clinical depression**, your medication, low iron from bleeding symptoms or (in women) heavy periods. If none is found and it is assumed to be a symptom of ITP, it is important that your physician should understand how it is affecting your life, as this is all part and parcel of your ITP journey. He may consider changing your medication or suggest coping strategies. Fatigue can make you forgetful, so keep a record of what is difficult for you, how you sleep, and anything you have found that eases or worsens your fatigue.

* <http://onlinelibrary.wiley.com/doi/10.1111/bjh.13385/abstract>

** *The clinical disorder of depression is a very common episodic, diagnosable and treatable condition. There are many short questionnaires that are excellent, accurate screening tools to identify depression.*

What else?

If you spend hours lying in bed or on the sofa do regular stretches and take occasional deep breaths. Not getting enough sunlight can exacerbate fatigue, so if you don't feel able to go outside and get some fresh air, spend time in a light and airy room. Try not to worry – fatigue is a fairly common symptom of ITP and most people manage to find strategies to fold it into their lives. If you have found a useful strategy do let us know so we can share it with others!

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