

FATIGUE IN IC/BPS PATIENTS: CAUSES, IMPACT & COPING

Fatigue is a potentially disabling condition that can cause mental and physical dysfunction, with a severe impact on the patient's relationships, home-life, employment and social life. It can cause physical incapacity, brain fog, inability to communicate to people around you, and an overwhelming sense of isolation.

Many IC/BPS patients suffer from fatigue, listlessness and lack of energy or drive. While fatigue is still frequently ignored, misunderstood, dismissed as psychosomatic or simply considered unimportant by many of the medical profession, it is also equally misunderstood by the patient's family and friends. This can create a very unsympathetic environment for a patient suffering from fatigue and make it much more difficult to cope with the condition.

As with everything in IC/BPS patients, there are huge variations in fatigue varying from mild and fluctuating at one end of the scale and very severe at the other end with an impact that may virtually paralyse the patient's life. Fatigue may on the one hand be temporary, the cause easily diagnosable and treatable, or it may be persistent, unexplainable and fail to respond to any treatment. A patient may have only physical fatigue, or a combination of physical and mental fatigue (known as brain fog).

One of the aspects that make fatigue so complex is that persistent tiredness or chronic fatigue can have multiple causes and any individual patient may be suffering from more than one cause of fatigue at the same time and therefore all of these will need to be addressed. Furthermore, it is certainly not always easy to see what the cause or different causes may be, especially as the symptoms from different types of fatigue may be similar and overlap.

An often overlooked cause of fatigue may be peripheral neuropathy/polyneuropathy which can sometimes occur with autoimmune diseases, particularly small fibre neuropathy which often goes undiagnosed.

Causes of fatigue

Causes of fatigue can be roughly grouped under the following main headings:

- Sleep disruption
- Medication
- Physical (organ-based) diseases
- Neurological disorders
- Psychological disorders
- Diseases without proven psychological or physical cause
- General

Sleep disruption

Lack of proper sleep is the first aspect that anyone is going to think of in relation to an IC/BPS patient. We know that IC/BPS patients vary greatly in their symptom levels, including night-time urination, and this can even fluctuate in an individual patient depending on whether the patient is in a flare or in remission. But even only 2 or 3 times a night on a regular basis can cause considerable tiredness because some people find it very difficult to get off to sleep again once they have got out of bed to go to the bathroom. The most severe IC/BPS patients or patients in a flare may be out of bed every 20 minutes or worse, even sitting all night on the toilet, or wrapped up in a blanket on the bathroom floor.

However, many other aspects can contribute either to being unable to get off to sleep or to frequent waking in the night, leading to extreme tiredness:

- pain, not only in the bladder but also elsewhere; many IC/BPS patients may have one or multiple other pain syndromes which may cause pain at night.
- Restless legs syndrome, itching, burning, tingling: all of these can prevent you from sleeping.
- Medications: all kinds of medication can cause insomnia.
- Patients may be woken up by noise: from a snoring partner, crying babies, noisy traffic etc.
- Too much light inside or outside the home, from streetlights or outside security lights.
- Anxiety, work stress, and the stress, worry and sometimes panic of coping with IC/BPS can all prevent sleep.
- Many diseases and disorders can cause sleeping disorders or insomnia, e.g. fibromyalgia, anaemia.

Therefore, each patient should carefully think about whether it is purely the bladder pain and need to urinate that is waking them (or keeping them awake), or whether something else has disturbed their sleep and they then feel their bladder discomfort and get out of bed. It may be purely the IC/BPS bladder in some patients, but in others perhaps a combination.

Physical and psychological impact of lack of sleep

“Frequent nocturnal awakenings, particularly during the first part of the night, decrease the restorative function of sleep and can cause daytime sleepiness and impaired cognitive function.”

(Chapple C. Introduction and conclusions. European Urology Supplements 6 (2007) 573–575)

According to the experts, proper, restorative sleep occurs in the first part of the night and it is likely to be this early part of the night that is most disturbed in IC/BPS patients. Adequate sleep is a basic requirement for good health. You need sleep for recuperation and restoration of physical and mental functioning. Without this proper sleep, a person deteriorates both physically and psychologically. The physical and psychological impact of sleep disruption is quite extensive and can have serious consequences as you can see from the list below:

- Fatigue and lack of energy
- Mood swings, irritability, tearfulness
- Lack of motivation
- Decreased concentration
- Memory lapses
- Motor performance impairment
- Disorientation
- Depression

(adapted from Marschall-Kehrel D. Update on nocturia: the best of rest is sleep. Urology. 2004 Dec;64(6 Suppl1):21-4)

Treating lack of sleep – useful tips for the IC/BPS patient

- It goes without saying that suitable treatment for the bladder pain, urgency and frequency and any other pain should have absolute priority.
- If the distance to the bathroom is too far, it might be a good idea for an IC/BPS patient to have a commode or an old-fashioned chamber pot or a portable camping toilet in the bedroom. The further the distance to the bathroom, the more time the body has to completely wake up, and the less likely it is to get off to sleep again when back in bed. A toilet facility close by can reduce the risk of falls in the night.

- Patients should reduce night-time urination as far as possible or advisable by limiting drinking in the evening and avoid consuming any food or drink that they know will irritate the bladder or food and drink that is likely to keep them awake. But they should make up for this by drinking plenty earlier in the day to avoid concentration of urine.
- If patients have to take medication that causes irritation in the bladder, they should either take it early in the morning or very late at night just before sleeping. But preferably change the medication to something that does not irritate the bladder.
- Ear-plugs can be a solution for patients kept awake or woken up by noise of any kind.
- If it is impossible to do anything about disturbing light, an eye-mask may help.
- If lack of sleep is partly caused by anxiety or stress, counselling may be needed. IC/BPS patients can become very anxious and panicky about their bladder disorder and its impact on their life and of course the fact that treatment may not be working. They worry continually about what the future may bring. And some counselling could help here.

Medication causing daytime drowsiness

While some medication can cause insomnia, other drugs can cause drowsiness all day long. Unfortunately, many treatments used for pain in IC/BPS have a sedative effect and make a patient feel like a zombie. However, many other drugs can have a sedative effect in some patients. Medicine intolerance experienced to varying degrees by some IC/BPS patients can make them react much more strongly to even the lowest dosages. It is therefore important to be aware that any medication could potentially either cause insomnia or daytime drowsiness or exacerbate existing chronic fatigue.

Physical (organ-based) diseases

Diseases causing tiredness include anaemia, hypothyroidism, heart failure, low blood pressure, infectious diseases including glandular fever. These can all be checked out by the doctor. Cancers also cause extreme fatigue. Any diseases causing chronic pain day in day out are very exhausting. Coping with a bladder disorder like IC/BPS is also very tiring because a patient can never really relax. They are constantly aware of the pain or irritation in the bladder and are exhausted by continually going to and from the bathroom.

Chronic fatigue

A special role is played here by systemic autoimmune diseases such as systemic lupus erythematosus and Sjögren's syndrome in which true **chronic fatigue** can be a totally disabling symptom. Chronic fatigue can also occur in fibromyalgia. When no identifiable disease or cause of the fatigue can be found, it is known as chronic fatigue syndrome.

Chronic fatigue is different to other forms of tiredness. A difference with the tiredness caused by lack of sleep is that autoimmune tiredness has no bearing on whether a person has slept well or not.

Chronic fatigue may fluctuate from week to week, month to month and year to year and it may wax and wane during the day with flares at specific times when patients feel flu-like, shivering, with a headache, total exhaustion and inability to think. They no longer have the energy to take any kind of action, to talk to people, pick up the phone or take a decision.

With chronic fatigue, patients lose their drive and motivation, they may have memory lapses, no concentration and experience confusion. Physically, they may feel unwell all the time and become exhausted after the slightest exertion. While rest may sometimes alleviate the fatigue for a short time, it soon returns when the patient is active again.

Advice to patients with chronic fatigue

Work out how to plan your routine each day depending on how you feel. If necessary, restructure your life, change your lifestyle. Do not take on more commitments than you can cope with. Learn to say no. Recognize when you are overdoing it before you collapse. Don't feel guilty about taking naps or siestas during the day. Discover how much exercise you need and can cope with. Take sufficient exercise, but

don't overdo it. With chronic fatigue, you have to learn how to pace yourself, learn how to manage physical and emotional stress. Avoid overdoing things at times when you feel a bit more energetic since this can cause rapid burnout. At those rare moments when you have a window of energy, it is so tempting to try to catch up with all those tasks that have been neglected and piled up. It is important at all times to build in periods of rest and relaxation.

All patients should bear in mind that fatigue or daytime drowsiness can make driving or use of machinery dangerous.

Psychological disorders

While depression can cause fatigue, chronic fatigue can itself cause depression. Since the very nature of IC/BPS symptoms can make patients depressed, it becomes a vicious circle from which it is difficult to escape.

Impact on the whole family

Fatigue impacts not only the patient but the whole family and can cause disruption of the life of everyone in the family, including children. It can make the patient unable to run the household, keep to any routine, create a normal environment for the family, lead a normal social life or have a normal relationship. The financial impact of chronic fatigue is a very important aspect for the patient since people with chronic fatigue may not be able to hold down a job.

SOME CAUSES OF FATIGUE

A. Sleep disruption

- night-time frequency
e.g. IC/BPS, OAB, CP, pelvic organ prolapse, polyuria
- timing of drinking (too much, too late)
- pain, itching, burning, restless legs
- medication -> insomnia or nightmares
- environmental disturbance
 - . noise
 - . light
 - . uncomfortable bed, too hot, too cold
 - . snoring, restless partner
- stress, anxiety, panic attacks

B. Medication causing fatigue, sleepiness, lethargy

e.g. opioids, anticonvulsants, antihistamines, anticholinergics, antidepressants, proton pump inhibitors, cough & cold remedies, chemotherapy, blood pressure medications, heart medications

C. Physical (organ-based) diseases

Anaemia
Hypothyroidism
Heart failure
Low blood pressure
Infectious diseases
Systemic autoimmune diseases
Neurological/neuropathy
Cancer

D. Psychological disorders

Depression
Burnout

E. Diseases without proven physical and psychological cause

Chronic fatigue syndrome
Fibromyalgia

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