

## Interstitial cystitis (IC) and associated disorders

### An overview for patients

by Jane Meijlink

*Studies and patient surveys have indicated that many patients with Interstitial Cystitis (Painful Bladder Syndrome, Bladder Pain Syndrome) may also have one or more non-bladder disorders or diseases, other chronic pain syndromes or undiagnosed symptoms in addition to having interstitial cystitis. Since IC patients are generally treated by a urologist or urogynaecologist, some of these disorders may go undiagnosed and consequently untreated. This underlines the need for a multidisciplinary approach.*

Associated disorders (also called *comorbidities* or *co-existing disorders*) that appear to occur more commonly in IC patients than in the general population include:

- allergy/hypersensitivity,
- fibromyalgia,
- gastrointestinal disorders: irritable bowel syndrome (IBS), inflammatory bowel disease (IBD),
- migraine
- rheumatoid arthritis,
- systemic lupus erythematosus (SLE)
- Sjögren's syndrome.
- vulvodynia,
- chronic fatigue

Men suffering from IC may also have chronic non-bacterial prostatitis (CP/CPBS) in addition to interstitial cystitis.

Associated disorders broadly fall into three main categories: allergy/hypersensitivity, pain syndromes and (systemic) autoimmune diseases.

The possible relationship between IC and other disorders that may co-exist with IC, and why these disorders should occur alongside each other in the same patient, is still unknown and is currently the subject of much interest and research. Since diagnosed IC patients are generally treated by either a urologist or urogynaecologist, some of these associated disorders may go undiagnosed and untreated. This underlines the need for a multidisciplinary approach. Both the doctors treating IC patients and the patients themselves should be on the alert for other symptoms that may indicate the presence of another disorder, since in some cases it might change the approach to treatment of the bladder disorder. (See table 1 which comprises a list of questions that may be useful as a first screening to assess the possibility of a patient with IC having associated disorders.) Furthermore, diagnosis and treatment of other disorders may greatly improve a patient's symptoms and quality of life and may even help to improve the IC symptoms.

#### **Autoimmune disease and IC**

One of the many theories concerning IC is that it might itself be an autoimmune disease.

Rheumatoid arthritis, systemic lupus erythematosus (SLE), Sjögren's syndrome and thyroid disorders are examples of autoimmune diseases. In autoimmune diseases, the immune system attacks the patient's own body. Some autoimmune diseases may be "organ specific", i.e. they attack one specific organ in the body (for example thyroid disorders). Others may be "generalized" or "systemic": this means that they attack many different organs and systems throughout the body.

Patients with both a diagnosed autoimmune disease and IC should be sure to inform their specialists of this fact, particularly if the autoimmune disease is diagnosed after the IC has been diagnosed, since this might mean using different types of medication to treat the IC (see below systemic treatment).

One problem with IC patients with symptoms indicative of autoimmune disease is that laboratory tests may reveal few or no abnormalities. The IC patients quite often do not fulfil all the criteria of any single specific disease. Why this occurs is still a mystery, but the result is that many sick patients may still be going undiagnosed and untreated. If an autoimmune disease is suspected, patients should be referred by their general practitioner to a special in internal medicine, immunology or rheumatology. It may also be necessary to see a gastroenterologist or neurologist.

#### - Systemic treatment

Some IC patients who display symptoms of autoimmune diseases in addition to IC may benefit from "systemic" treatment (i.e. treatment of the whole body with one medication), for example hydroxychloroquine and sulphasalazine (commonly used to treat inflammatory bowel disease and rheumatic diseases) or corticosteroids such as prednisolone, dexamethasone or hydrocortisone. Some patients have reported a substantial improvement in their IC symptoms through this treatment. However, here too treatment is highly individual and every patient is different.

#### **Multiple pain syndromes**

In recent years, attention has been drawn to the fact that some IC patients appear to suffer from not simply multiple disorders but also **multiple pain syndromes**, affecting different parts of the body and not only the pelvic organs. Some patients suffer from a variety of combinations of pain conditions, for example: IC, chronic prostatitis (CP/CPPS), irritable bowel syndrome, vulvodynia, fibromyalgia, migraine, temporomandibular disorder, and other painful disorders. It is still a mystery why this affects some IC patients and not others, since some IC patients appear only to have a bladder disorder.

The NIH/NIDDK **Multidisciplinary Approach to the Study of Pelvic Pain (MAPP)** in the USA is currently studying these pain syndromes together with IC and CP/CPPS to see what they have in common and what the risk factors are and will endeavour to characterize patients into types (*phenotyping*) for treatment purposes. This is an extensive, at least 5-year study that started in 2008.

#### **Many pain theories**

So far, pain researchers' theories concerning the occurrence of multiple pain syndromes include central nervous system involvement (possibly *central sensitization*), damage or inflammation in one organ of the body affecting another organ or system either due to central nervous system processing or to so-called *cross-sensitization* or *cross-talk* with inflammation in one organ causing inflammation in another, abnormalities of autonomic function and most recently limbic dysfunction in the brain. Bearing in mind the variations in

pain felt by women during their menstrual cycle, it is also theorized that there may be hormonal involvement in pain perception in these women.

**Table 1. Questions to assess the possibility of an IC patient having associated disorders as a useful first screening for the presence of these diseases**

**1. Allergy**

1.1 Have you ever had shortness of breath, shock, angioedema, pruritis or urticaria after exposure to or ingestion of a particular drug, food, pollen, or contact with an animal?

**2. Asthma**

2.1 Do you have recurrent episodes of dyspnoea, coughing and wheezing?

2.2 Are these symptoms seasonal, or do they occur shortly after exposure to antigens such as animal dander, feathers, dust mites or mould?

**3. Crohn's disease and ulcerative colitis**

3.1 Do you often have abdominal cramp, particularly after meals?

3.2 Have you lost weight? (what was your normal weight and what did you weigh at that time?)

3.3 Do you often have diarrhoea or loose stools?

3.4 Do you often see red blood with stools?

3.5 Have you in the past had unexplained anaemia?

3.6 Do you have/have you had fistulas?

**4. Fibromyalgia**

4.1 Do you have diffuse musculoskeletal achiness, stiffness or exaggerated tenderness?

4.2 Do you have visible swelling of the joints? (suggests another disease)

4.3 Do you have paraesthesia, non-restorative sleep and are you easily fatigued?

**5. Irritable bowel syndrome**

5.1 Do you often have abdominal pain or discomfort in association with defecation?

5.2 Do you have abdominal pain in association with a change in bowel habit?

5.3 Do you have disordered defecation such as abnormal stool frequency, abnormal stool form, defecation straining or urgency, a feeling of incomplete bowel emptying, mucus with stools or a bloated or swollen abdomen?

**6. Rheumatoid arthritis**

6.1 Do you have chronic symmetrical swelling and pain in multiple joints?

6.2 Do you have generalized morning stiffness lasting more than 1 hour?

**7. Sjögren's syndrome**

7.1 Have you had daily, persistent, troublesome dry eyes for more than 3 months?

7.2 Do you have a recurrent sensation of sand or gravel in the eyes?

7.3 Do you use tear substitutes more than 3 times a day?

7.4 Have you had a daily feeling of dry mouth for more than 3 months?

7.5 Have you had recurrently or persistently swollen salivary glands as an adult?

7.6 Do you frequently drink liquids to aid in swallowing dry food?

**8. Systemic lupus erythematosus**

8.1 Does the sun cause redness on areas of your skin exposed to a normal amount of sunlight?

8.2 Do you often have mouth ulcers or sores?

8.3 Do you often have painful swelling of the joints in your hands and/or feet?

8.4 Have you ever had pericarditis, pleurisy or nephritis?

*(Source: Joop P. van de Merwe MD, PhD)*

## **A brief look at a few of the disorders which may co-exist with interstitial cystitis**

### **ALLERGY/HYPERSENSITIVITY:**

Many IC patients suffer from allergy/hypersensitivity, including food, chemicals and drugs. Allergies can affect the skin, airways and sometimes organs. Examples of allergy include asthma, rhinitis, urticaria (nettle-rash), eczema and anaphylaxis. True allergies can be identified by allergy tests. In some cases, patients receiving antihistamines for their allergy find that this treatment also has a beneficial effect on their IC bladder symptoms.

However, not all hypersensitivity reactions are true allergy and may in fact be a question of non-allergic hypersensitivity, often known as intolerance. The problem with this non-allergic hypersensitivity is that reactions to drugs may be unpredictable and variable, are often a question of trial and error and largely impossible to “diagnose” by standard tests. Non-allergic hypersensitivity is still a relatively unexplored, unresearched field and particularly so in relation to the drug intolerance (often multiple drug intolerance) found in some IC patients. Some IC patients may also have multiple chemical intolerance and feel sick, dizzy and faint if there are chemicals in the air or if perfumed products or chemicals touch their skin. At present, it is unknown why some IC patients have these problems and others not. It is interesting to note that multiple drug intolerance and multiple chemical intolerance are also found typically in patients with fibromyalgia.

Drug intolerance may affect, for example, cognitive functioning, eyesight and balance and cause dizziness, faintness, headache, general malaise, fatigue or drowsiness.

Patients with drug intolerance often respond better to intravesical treatment for their IC where less of the drug is absorbed into the system.

Finding a solution to drug intolerance would make it considerably easier to find an adequate treatment for many patients, thereby relieving the anxiety that multiple drug intolerance may cause and greatly improving their quality of life. And of course we should not forget that expensive drugs are being thrown away.

### **CHRONIC NON-BACTERIAL PROSTATITIS:**

Chronic non-bacterial prostatitis/chronic pelvic pain syndrome (CP/CPPS), sometimes called prostate pain syndrome, is the most common form of prostatitis. The older term prostatodynia is also sometimes used to describe this painful prostate condition. Unlike acute or chronic bacterial prostatitis, it is not caused by any identifiable infection and therefore does not respond to treatment with antibiotics. It may be inflammatory or non-inflammatory. While its cause is unknown, one theory that has been suggested is that it could be of autoimmune origin. For further detailed information see: [www.prostatitis.org](http://www.prostatitis.org)

### **DEPRESSION:**

Depression is experienced by many people in the general population, either occasionally or persistently but may particularly occur in patients with chronic disorders such as IC. Sometimes it is a question of being temporarily “down” or “moody” or “sad” or unable to cope, but sometimes it is more serious and needs treatment and professional counselling. Some patients may not actually realize that they are suffering from depression and this may partly be due to confusing usage of the word depression. People so often say that something that has occurred has made them “so depressed” when in fact they mean that they are upset or sad or shocked about a specific incident. Under normal circumstances, they will adjust to the situation and soon recover. However, in cases of true depression, the sad or

down feeling will persist. There may be multiple effects: people's weight can go up or down, they may sleep too much or too little, may feel tired all the time and have no energy, have feelings of guilt, feel worthless, experience confusion or forgetfulness (*cognitive impairment*), have suicidal thoughts. Depression can make it impossible to work, study and cope with or enjoy everyday life. While depression may be caused by psychiatric disorders, it may also form part of a syndrome of symptoms in chronic diseases, as has been documented in systemic lupus erythematosus, and may potentially occur in any disease with a neurological component including pain syndromes. "Mood" disorders are caused by chemical imbalances in the brain. This may be caused by an illness, by hormone imbalance, even by certain medications. Treatment may be aimed at changing the chemical imbalances in the brain.

In IC patients, it may be a question of a temporary inability to cope which can be helped by good support and a sympathetic approach from their doctor, by a patient support group, by support in the home environment. If more serious, it should be treated with medication combined with counselling. Depression in IC patients may be combined with anxiety and/or panic attacks and this can respond to treatment. Above all, patients should not be afraid or feel guilty about admitting to their doctor that they are suffering from depression. Professional help should always be sought for suicidal patients.

*Further reading:*

*The National Institutes of health have a useful booklet on depression online:*

<http://www.nimh.nih.gov/health/publications/depression/complete-index.shtml>

*and also a specialised leaflet on Men and Depression to be downloaded at:*

<http://www.nimh.nih.gov/health/publications/men-and-depression/complete-index.shtml>.

*Wikipedia also has a useful article on Depression – differential diagnoses*

[http://en.wikipedia.org/wiki/Depression\\_\(differential\\_diagnoses\)](http://en.wikipedia.org/wiki/Depression_(differential_diagnoses))

*If you have access to UpToDate [www.uptodate.com](http://www.uptodate.com), you will find information on this topic for both patients and professionals.*

#### **FATIGUE:**

Many IC 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 environment. This can create a very unsympathetic environment for a patient suffering from fatigue and make it so much more difficult to cope with the condition.

As with everything in IC patients, you find huge variations in fatigue with a wide spectrum 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.

One of the aspects that makes fatigue so complex is that persistent tiredness or chronic fatigue can have multiple causes and any given 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. And 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.

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### **Causes of fatigue**

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

- Sleep disruption
- Medication
- Physical (organ-based) diseases
- 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 patient. We know that IC patients vary greatly in their symptom levels, including night-time voiding, 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've got out of bed. The most severe IC 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, we should not forget that 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 patients 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.
- You 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 can all keep you awake.

So each patient should carefully think about whether it is purely the bladder pain and need to void that is waking you up, or whether something else has disturbed your sleep and you then feel your bladder discomfort and get out of bed. It may be purely the IC bladder in some patients, but in others perhaps a combination.

### **Physical and psychological impact of lack of sleep**

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 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 patient**

- It goes without saying that suitable treatment for the bladder pain and the frequency and any other pain should have absolute priority.
- If the distance to the bathroom is too far, it's also a good idea for an IC patient to have a commode or an old-fashioned chamber pot or a portable camping toilet in the bedroom. The further you have to walk to reach the bathroom, the more time your body has to completely wake up, and the less likely you are to get off to sleep again when you're back in bed.
- Cut down night-time voiding as far as possible by limiting drinking in the evening and avoid consuming any food or drink that you know will irritate the bladder or food and drink that is likely to keep you awake. But make up for this by drinking plenty earlier in the day to avoid concentration of urine.
- If you have to take medication that causes irritation in the bladder, either take it early in the morning or very late at night just before sleeping. But preferably change your medication to something that does not irritate the bladder. And this is very individual.
- If you are being kept awake or woken up by noise of any kind, try using ear-plugs.
- If you can't do anything about disturbing light, wear an eye-mask.
- If lack of sleep is partly caused by anxiety or stress, counselling may be needed. IC 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, so many treatments used for pain in IC have a sedative effect and make you feel like a zombie. However, many other drugs can have a sedative effect in some patients. We should not forget here the role played by the medicine intolerance experienced to varying degrees by some IC patients. This 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 is also very tiring because you can never really relax. You always feel that 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 **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 you have 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 you then feel fluey, shivering, with a headache, total exhaustion and inability to think. You 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 you lose your drive, your motivation, you may have memory lapses, no concentration and experience confusion. Physically, you feel unwell all the time. Your body feels uncomfortable, it aches and you can't tolerate tight clothes. You become exhausted after the slightest exertion. While rest may sometimes alleviate the fatigue for a short time, as soon as you are busy again the fatigue returns.

#### **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**

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

#### **For further information, including treatment, see:**

Sjögren's syndrome. Information for patients and professionals by Dr Joop P. van de Merwe.

Chapter 5 Treatment: [www.painful-bladder.org/pdf/ch5.pdf](http://www.painful-bladder.org/pdf/ch5.pdf),

Chapter 6 Fatigue: <http://www.painful-bladder.org/pdf/ch6.pdf>

#### **FIBROMYALGIA SYNDROME (FMS)**

Fibromyalgia is a chronic, debilitating multisystem pain syndrome of unknown cause with widespread musculoskeletal pain and tenderness. The term fibromyalgia means pain in the soft fibrous tissues of the body: muscles, ligaments and tendons and in multiple tender points, but inflammation is not believed to be a characteristic of FMS. Current theory concerning the cause focuses on the theory of central sensitization. Fibromyalgia may be accompanied by a range of symptoms including: morning stiffness, extreme fatigue, sleep disturbances, drug intolerance, irritable bowel syndrome, facial pain or pain around the temporomandibular joint (TMJ), pelvic pain and bladder disorders. Patients with FMS are also prone to tingling, numbness, dizziness and cognitive or memory disorders. FMS can vary in severity from person to person: some patients may have a mild form of discomfort, while others may suffer from a very severe and disabling form of FMS with extreme fatigue and pain. Some researchers have suggested that the term FMS may in fact include several sub-

groups. Like IC, the course of this condition can be variable with exacerbations and remissions. For further information:

<http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001463/>, <http://www.fmaware.org/>,  
<http://www.ukfibromyalgia.com/>

#### **RHEUMATOID ARTHRITIS (RA):**

Rheumatoid arthritis is a chronic systemic, autoimmune connective tissue disease that mainly affects the synovial membranes of joints and is characterised by pain, swelling and stiffness of joints, usually symmetrically. As the disease progresses, the ligaments are damaged, there is erosion of the bone, resulting in deformity of the joints. This deformity of the joints is an important difference with other rheumatic diseases such as Sjögren's syndrome.

Further information: <http://www.arthritis.org/rheumatoid-arthritis.php>

#### **GASTROINTESTINAL DISORDERS:**

Gastrointestinal disorders are frequently seen in association with IC.

- **Irritable bowel syndrome (IBS)**, a functional bowel disorder, is the most common disorder in IC patients, with symptoms including abdominal pain or cramp, alternating diarrhoea and constipation and a bloated feeling due to gas formation.
- **Inflammatory bowel disease (IBD)**, a group of disorders comprising Crohn's disease and ulcerative colitis, with weight loss, blood in the stools and diarrhoea at night, is also found more commonly in IC patients than in the general population. Commonly suspected to be of autoimmune origin.

The National Digestive Diseases Information Clearinghouse (NDDIC) has useful information on IBS at:

<http://digestive.niddk.nih.gov/ddiseases/pubs/ibs/index.aspx> and on IBD at:

<http://digestive.niddk.nih.gov/ddiseases/topics/IBD.aspx>

See also: <http://www.painful-bladder.org/pdf/ch9.pdf> for information on gastrointestinal disorders in general and in combination with Sjögren's syndrome by Dr J.P. van de Merwe.

#### **SENSITIVE SKIN:**

Many IC patients have a problem with dry, itchy, sensitive skin. It is advisable to keep the skin well moisturized with cream or lotion for sensitive skin to reduce the dryness and this may also reduce some of the itchiness. Keep away from chemicals such as household cleaning products (wear protective gloves) and perfume. Use cosmetics, soap and shampoo for hypersensitive skin. Do not use (perfumed) soap or any other products around the vulvar/genital area. Take care with contraceptive devices containing chemicals such as condoms and spermicidal creams. If possible, wash your clothes with products specially made for sensitive skin that do not contain perfume. Wear cotton underwear and loose clothes. Avoid touching garden plants that may cause skin reactions. Take care in the sun if you find that your skin is sensitive to sunshine.

#### **SJÖGREN'S SYNDROME:**

Sjögren's syndrome is a chronic, autoimmune disease of unknown cause in which lachrymal (tear) and salivary glands malfunction. Its hallmark symptoms are sore, irritated eyes and dry mouth with a need to drink when eating because dry food otherwise sticks to the mouth and cannot be chewed or swallowed properly (so-called "cracker sign"). It is a systemic disease and may therefore affect many organs and systems of the body. Nine out of ten patients are women. Although it can affect any age group, the average age of onset is the late 40s. This disease is traditionally classified into two types: primary Sjögren's syndrome where the

disease occurs alone and secondary Sjögren's syndrome when it occurs in association with another disease such as SLE, systemic sclerosis, rheumatoid arthritis and polymyositis /dermatomyositis. While some patients may experience only mild symptoms, in others their quality of life is seriously impaired by debilitating symptoms and extreme fatigue. It can often take many years for a patient to get a diagnosis, particularly in patients where the typical combination of irritated eyes and dry mouth is not recognized in patients in whom no autoantibodies can be seen and ESR is normal. In recent years, clinical studies, observation and surveys have led to an increased awareness that IC and Sjögren's syndrome can occur in association with each other and that Sjögren's syndrome may be being underdiagnosed in IC patients.

Further information: [http://www.painful-bladder.org/pbs\\_ic\\_ass\\_dis.html](http://www.painful-bladder.org/pbs_ic_ass_dis.html) where you will find an entire book on Sjögren's syndrome divided into separate chapters, by Dr J.P. van de Merwe.

#### **SYSTEMIC LUPUS ERYTHEMATOSUS (SLE):**

Systemic Lupus Erythematosus (SLE), sometimes referred to as simply Lupus, is a chronic, inflammatory, autoimmune connective tissue disease, involving many organs, with unpredictable flares and remissions. It may involve joints, skin, kidneys, lungs, heart, vascular system, gastrointestinal tract, central or peripheral nervous system and the bladder. A painful bladder disorder in SLE patients was known in the past as 'Lupus Cystitis', but is now generally referred to as IC. The symptoms and severity of SLE can greatly vary from patient to patient and may also undergo change in an individual patient over time. As in the case of IC, there is a high predominance of women patients.

Further information: <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001471/>  
<http://www.lupusresearch.org/?gclid=CNiukrPSwaoCFYKFDgod2y-a5g>

#### **THYROID DISORDERS:**

The thyroid gland is situated at the front of the neck below the skin and muscle layers. It has the form of a butterfly with the two wings represented by the right and left lobes that wrap around the trachea. The function of the thyroid gland is to make thyroid hormone which regulates the body's metabolism and is essential for mental and physical development. The thyroid gland is prone to two extremes of disorders:

- Hyperthyroidism (it makes too much hormone)
- Hypothyroidism (it makes too little hormone).

Chronic thyroiditis is an inflammatory condition of the thyroid caused by an autoimmune disorder in which lymphocytes invade the tissues of the gland. The most common type of thyroiditis is Hashimoto's thyroiditis. It includes swelling of the thyroid gland and partial or complete failure to secrete thyroid hormones. Women are affected more than men.

#### **VULVODYNIA**

Vulvodynia (or vulvar pain syndrome) is a distressing, painful condition, difficult to diagnose and difficult to treat. It is a broad collective term used to describe any chronic pain condition of the vulvar area and embraces a number of different types of vulvar disorder causing chronic or intermittent pain, burning, rawness and pain with sexual intercourse. There are two main types of vulvar pain:

- **Localized vulvodynia (vestibulodynia, formerly known as vulvar vestibulitis)** is pain or burning sensation caused by something touching the vestibule (entrance to the vagina). Pain is caused by sexual intercourse, insertion of tampons, riding a bicycle,

gynaecological examination, tight clothes or any situation where the vestibule is touched. There is usually no pain if the area is not touched. Vestibulodynia is diagnosed by touching the vestibule with a Q-tip. Even light pressure such as this can cause pain.

- **Generalized (dysesthetic) vulvodynia** is pain, burning, stinging or rawness on or around the vulva, labia, vestibule, clitoris or perineum most of the time, whatever they are doing. It is not dependent upon touch or pressure but this can nevertheless exacerbate the symptoms. Urination may cause pain and burning. Sexual activity is sometimes so painful as to be impossible, while at other times there may be little or no pain. Generalized vulvodynia is diagnosed when there is a history of constant pain with no visible cause or other identifiable disorder such as infection.

For further information on vulvodynia, see: [www.nva.org](http://www.nva.org) (National Vulvodynia Association)

**For further detailed information on IC and associated disorders on this website:**

[http://www.painful-bladder.org/pbs\\_ic\\_ass\\_dis.html](http://www.painful-bladder.org/pbs_ic_ass_dis.html) :

“Interstitial cystitis and associated disorders” by Joop P. van de Merwe MD

“Interstitial cystitis and gastrointestinal disorders” by Joop P. van de Merwe MD  
as well as detailed information on Sjögren’s syndrome by the same author.

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