

EURORDIS.ORG

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First symptom ...

... diagnosis ...

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Many will have been told time and time again that "it's all in the mind".

1. First Symptom

The symptoms may begin spontaneously at any age for no apparent reason with spontaneous flares and remission. Starts with persistent or recurrent symptoms of pain, pressure or discomfort related to the bladder and usually accompanied by a frequent and urgent need to urinate throughout the day and night (<60 times a day). The pain may be not responding to painkillers. The symptoms may be confused with a urinary tract infection (cystitis) or other confusable diseases.

Note: Recognition and referral to a specialist in interstitial cystitis / bladder pain syndrome. The most important and immediate need is pain management, but often pain and discomfort is underestimated.

Ideally: To have a clinician that takes seriously the symptoms. It is important to have pain management and to be directed towards the Patient Organization that can guide the patient towards the correct way to cope with this disease

2. Diagnosis

Due to the lack of specific tests or markers, diagnosis of IC/BPS based on: i. Symptoms: pain or discomfort or pressure or other unpleasant sensation, accompanied by other urological symptoms such as urgency and/or frequency. ii. Exclusion of any identifiable infection, disease or disorder. Diagnosis may be supported by cystoscopic findings with or without hydrodistension; urodynamics study; biopsy findings

Note: Unfortunately, delay of diagnosis is common, with an average time of 5-10 yrs. Many patients will have seen numerous specialists before finally getting the right diagnosis. Patients who still have no diagnosis can become absolutely desperate with pain, frequency and frustration to the point of being suicidal.

Ideally: Patients feel comforted when their long history of pain and debilitating symptoms is at last being taken seriously by the medical profession. And this makes them feel a spark of hope.

3. Treatment

Treatment is highly individual to each patient is different includes: i. one or more oral drugs, topical drug treatment - vaginal and rectal treatment for pain; ii. bladder instillations or intramural injections; iii. bladder distension; iv. Neuromodulation / electrotherapy; v. different forms of physical therapy; vi. myofascial therapy; triggerpoint therapy and pelvic floor relaxation; viii. exercise; vii. sex therapy/counselling; ix. intravesical and intramural bladder treatment

Note: The need is to receive a treatment that is tailored to the patient's symptoms and needs valued with a multidisciplinary approach. This is to maximize the effects of treatment, it is important to determine which symptom or symptoms are causing the most problems at each stage of the disorder in each individual patient.

Ideally: Patient's should be guided and educated on their condition.

4. Surgery

Surgery includes surgical interventions on the nervous system and surgery on the bladder itself – i. Laser ablation, electrocoagulation or transurethral resection (TUR) for Hunner lesion; ii. Neuromodulation / electrostimulation (nerve stimulation). Surgery on the bladder and lower urinary tract. IC/BPS is a complex disease and surgery may lead to other complications. Surgery includes bladder augmentation, urinary diversion, partial or complete cystectomy and should only be undertaken by experienced surgeons.

Note: Surgery is not something to be undertaken lightly since IC/BPS is a complex disease and surgery may lead to other complications.

Ideally: It is important to discuss clearly with patients exactly what is involved in affording surgery and the potential side effects and consequences.

5. Life-long Follow Up

The disease has to be followed constantly because symptoms of IC/BPS do not go away, they keep on returning.

Note: Treatments should be paired with Lifestyle coaching for behavioural changes, stress reduction and relaxation therapy. Patients soon learn that the symptoms of IC/BPS can be exacerbated by physical or emotional stress.

Ideally: IC Centers should provide professional counselling to learn how to cope with the impact of the disease on their lives and reduce the stress, depression and anxiety which the disease causes.