



York Teaching Hospital
NHS Foundation Trust

Bladder Pain Syndrome or Interstitial Cystitis

Information for patients, relatives and carers

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Introduction

Bladder Pain Syndrome (BPS) or Interstitial Cystitis (IC) is a condition causing various urinary symptoms and pain. Unfortunately, IC or BPS is a poorly understood disease and is often not recognised by many doctors particularly when the main symptom is pain.

What are the causes of Interstitial Cystitis or Bladder Pain Syndrome?

Unfortunately, there is as yet no answer as to why people develop Interstitial Cystitis or Bladder Pain Syndrome. It is much commoner in ladies.

Probably 80 percent of sufferers are female. Though the word cystitis is included in the name of the disease, this does not mean that antibiotics will cure the problem.

Cystitis is the medical word for inflammation of the bladder. There are many types of inflammation of the bladder. Classical cystitis that people suffer from should technically be called bacterial cystitis.

Interstitial Cystitis, however, means that the bladder inflammation is in the tissues of the bladder wall itself. We do not know how this inflammation starts in the wall of the bladder. One theory is that the lining of the bladder becomes damaged, often because of classical bacterial infection cystitis. This then allows urine to seep into the wall of the bladder causing what is known as chronic inflammatory response. This then causes all the symptoms that patients with IC/BPS develop.

What are the symptoms?

Some or all of these symptoms may be present.

- **Frequency**

This can occur during the day or night time. The patient has a desire to empty their bladder very regularly.

- **Urgency**

This is a sensation of needing to get to the toilet immediately. This can occasionally be so bad that the patient suffers urinary incontinence before they reach the toilet.

- **Pain**

Pain can occur in the abdominal, pelvic, urethral (urine pipe), or vaginal areas. The pain may occur at any time but often worse when the bladder fills and is then relieved once the bladder is emptied; though it can take several minutes for the pain to settle after emptying the bladder. Pain may also occur with sexual intercourse.

How can Interstitial Cystitis or Bladder Pain Syndrome be diagnosed?

This can be very difficult in particular when pain is the main element of the patient's symptoms as often they are often referred to specialties other than Urology. It is unfortunate that, at the moment, other specialities are not always aware of the diagnosis of IC/BPS causing pain.

MSU (Mid-Stream Urine)

A urine sample is always taken to exclude classical bacterial infection.

Cystoscopy

A cystoscopy under general anaesthetic (where you are put to sleep) is performed to make the diagnosis. At the time of cystoscopy, typical characteristic features are seen in the bladder. In particular, bleeding after the bladder has been stretched under general anaesthetic. This finding is characteristic of IC/BPS.

A biopsy (a sample of tissue) of the bladder is often taken. This is to rule out any other diagnosis.

Ultrasound Examination

Often the patient has an ultrasound scan of the kidneys, the uterus and ovaries to exclude any other diagnosis.

What treatments are used?

Unfortunately, at the moment, there is no cure for IC/BPS. No one treatment works in all patients. Therefore, each treatment has to be tried until a patient finds some help.

Bladder Distension

This means that the bladder is gently stretched under general anaesthetic. This can be very helpful in some patients particularly those with urinary frequency and urgency. However, it often does not have a lasting effect.

When the bladder is stretched, there is a very rare risk that the bladder is punctured (less than one in 50 chance). In this case you might require a catheter for a short period but this small bladder puncture will almost always resolve quickly without any further complications.

Cystistat or Hyacyst (Hyaluronic Acid)

This medicine has to be put into the bladder using a catheter and given once a week for six weeks and then monthly if it helps your symptoms.

DMSO (Dimethyl Sulphoxide)

This medicine has to be put into the bladder using a catheter (thin/lubricated tube). The patient then holds the medication in the bladder for 15 minutes. It is usually given fortnightly for eight to ten weeks. DMSO works by allowing the lining of the bladder to heal and therefore stopping urine entering the deep tissues of the bladder and causing pain. It is quite common for patients to give off an aroma of garlic after treatment, which lasts for two to three days.

Antidepressants and pain relief tablets

Certain antidepressant drugs, such as Amitriptyline, can be helpful in treating IC or BPS. We are not using these drugs because we feel the patients are depressed. It is because one of the side effects of this drug is to calm the bladder down. The other side effects are that these types of drugs can cause nausea, constipation and drowsiness. These types of symptoms often settle after one month of taking them.

A similar drug can be helpful. This is known as Gabapentin which works on the nerve pathways to relieve pain.

Once a Day Antibiotics

Low dose, once daily antibiotics can be helpful for short periods of time to relieve symptoms. This is because they reduce the inflammation in the bladder caused by the condition.

Elmiron

This drug has a full product license in the USA, but has to be given on a named patient basis in the UK. It is based on another drug called Heparin, which is needed to repair the lining of the bladder and is taken as one 100mg tablet three times a day. As Heparin is used to thin the blood in other conditions there is a theoretical risk of bleeding whilst taking Elmiron, which in practice seems very rare. The commonest side effect is diarrhoea that occurs in around one in ten patients. Elmiron takes three to six weeks to be fully effective so patience is required, as like other treatments in IC/BPS it does not work immediately.

Diet

Certain people believe that elimination of certain foods and drinks from their diet can help. Please see diet sheet provided on page 13 to 14. It is suggested that you try avoiding the foods and drinks listed. If you find there is any benefit, continue to avoid these foods. If there is no improvement, you can start introducing these foods into your diet again.

Surgery

There is, unfortunately, no simple operation that can cure this problem. There are various complex operations available which will be discussed with you by your surgeon should they become necessary.

Non-Traditional Treatments

There are many non-traditional treatments available such as acupuncture, reflexology, homeopathy etc. If you think you would find any of these helpful, we have no objection to you seeking help from alternative therapies.

Reducing Stress

IC or BPS is a distressing condition. Quite often the patients have sought medical help for many years and have become despondent that no one can give them a diagnosis or offer any help. Many patients find that once a definite diagnosis is made it is easier to live with this condition. Stress can sometimes make the symptoms of IC/BPS worse. Therefore, it is suggested that if patients find stress is a definite factor in their problem that they learn basic relaxation techniques.

Various books and tapes are available from good booksellers.

Clothing

Some patients find that it is advantageous to wear loose clothing. If possible it may be advantageous to avoid clothing that puts pressure on the waist and abdomen i.e. avoid belts and tight trousers. It is often useful to wear cotton underwear.

Interstitial Cystitis and Bladder Pain Syndrome – Diet Sheet

Please note that this list has been taken from an American book and therefore some of the foods will not be available in this country.

The first thing to do following your diagnosis is look at the list of foods below and if you think that any of them make your bladder symptoms worse you should then avoid them. A period of at least three months experimentation will probably be needed to decide which foods and drinks to avoid.

Acid foods to be avoided

Apple Juice	Lemon Juice
Apples	Peaches
Cantaloupes (A type of melon)	Pineapple
Carbonated Drinks	Plums
Chillies (Spicy food)	Strawberries
Citrus Fruits (Lemons, limes, oranges etc.)	
Coffee	Tea
Cranberries	Tomatoes
Grapes	Vinegar
Guava	White Wines

Foods high in Tyrosine, Tyramine, Tryptophan and Aspartate to be avoided

Avocados

Bananas

Beer

Brewer's Yeast

Canned Figs

Champagne

Cheeses (soft)

Chicken Livers

Chocolate

Corned Beef

Cranberries

Nutra Sweet

Nuts

Onions

Pickled Herring

Pineapple

Prunes

Raisins

Rye Bread

Saccharine

Sour Cream

Some Wines

Soya Sauce

Yoghurt

Further support

Bladder Health UK, previously known as The Cystitis and Overactive Bladder Foundation (COB) provides a wide range of support, relevant information and resources that might be helpful.

Visit www.bladderhealthuk.org for more information.

You may also find further information at the BAUS (British Association of Urological Surgeons) website www.baus.org.uk.

Go to the patients section of the website to find useful information relating Bladder Pain Syndrome/Interstitial Cystitis.

By clicking on the listed headings you can also learn more about investigations, surgery and treatments relevant to you.

e.g. “I’m told I need.....cystoscopy”

Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact:

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Teaching, training and research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email pals@york.nhs.uk.

An answer phone is available out of hours.

Leaflets in alternative languages or formats

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