



York and Scarborough
Teaching Hospitals
NHS Foundation Trust

Bladder Pain Syndrome (Interstitial Cystitis)

Information for patients, relatives and carers

① For more information, please contact:

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Introduction

Bladder Pain Syndrome (BPS) which used to be called Interstitial Cystitis (IC) is a condition causing urinary symptoms and pain. Unfortunately, BPS is a condition which is not fully understood. As the symptoms can mimic other bladder problems it is important to rule these other problems out before a diagnosis is made.

What is Bladder Pain Syndrome?

Unfortunately, there is as yet no convincing explanation for why some people develop Bladder Pain Syndrome and others do not. It is much more common in women, and around eight in 10 of those people who do have symptoms are female. Though the word cystitis is included in the old name for the condition, this does not mean that antibiotics would be helpful.

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.

One theory about why Bladder Pain Syndrome happens is that the lining of the bladder becomes damaged, often following a bout of urinary tract infection. Causing what is known as chronic inflammatory response. This then may result in all the symptoms that patients with BPS develop.

What are the symptoms?

Some or all of these symptoms may be present.

- **Urinary Frequency**

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

- **Urinary Urgency**

This is a sensation of needing to get to the toilet immediately which cannot be delayed. This urge can sometimes be so strong that the patient leaks urine 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; it can then take several minutes for the pain to settle after emptying the bladder. Pain may also occur with or after sexual intercourse.

How is Bladder Pain Syndrome diagnosed?

As pain can be a key element of the person's symptoms, patients are sometimes referred to specialties other than Urology. For this reason it can take time to reach a diagnosis of BPS. Equally, as there is no specific test for BPS it can take time to exclude other causes for the symptoms.

MSU (Mid-Stream Urine)

A urine sample is always taken to exclude classical bacterial infection. Sometimes the urine is then sent away for testing to look for a bacterial cause.

Cystoscopy

A cystoscopy (a look inside the bladder) under general anaesthetic (where you are put to sleep) is performed to assist with the diagnosis of BPS. At the time of cystoscopy, typical characteristic features of BPS are seen in the bladder. 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 BPS. No one treatment works in all patients. Therefore, each treatment has to be tried until a patient finds some relief.

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.

Treatments delivered into the bladder (e.g. Sodium Hyaluronate)

This medicine has to be put into the bladder using a catheter. You keep it in for an hour or so then empty the bladder. It is given once a week for six weeks and then monthly if it helps your symptoms.

Pain management tablets

Certain pain management drugs, such as amitriptyline or gabapentin, can be helpful in treating BPS by settling the nerve pathways. The other side effects of this medication can include dry mouth, nausea, constipation and drowsiness. These types of symptoms often settle after one month of taking them.

Elmiron

This medication is taken by mouth three times a day. Because it has mild blood thinning properties, it may not be suitable if you are already taking any blood thinning drugs. Elmiron takes three to six weeks to be fully effective, so patience is required. As with other treatments for BPS it does not work immediately.

If you are prescribed Elmiron you will need to have eye tests in order to ensure it is safe for you to take. Reported side effects have happened to a small amount of patients taking Elmiron including maculopathy, hair loss, nausea and headaches. These do not happen to everyone and stopping the medication will reverse the effect.

Elmiron is based on another drug called Heparin, which is used to thin the blood. Therefore 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.

Diet and fluids

Certain people find that elimination of certain foods and drinks from their diet can help. Please see diet sheet provided on page 11 to 12. 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 or meditation. If you think you would find any of these helpful, we have no objection to you seeking help in this way. There is no evidence base for these therapies, however we would definitely not recommend unlicensed Chinese or herbal treatments which could make your bladder worse or make you acutely unwell.

Reducing Stress

BPS is a distressing condition. Quite often people 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 BPS worse. Therefore, it is suggested that if patients find stress is a definite factor in their life, that they learn basic relaxation techniques.

Clothing

Some patients find that it is advantageous to wear loose clothing. If possible, avoid clothing that puts pressure on the waist and abdomen i.e. avoid belts and tight trousers/jeans. Wear cotton underwear and avoid thongs or g-strings.

Interstitial Cystitis and Bladder Pain Syndrome – Diet Sheet

Any person experiencing bladder irritation symptoms and/or bladder pain may benefit from changing their diet and fluid intake. The key is to avoid acidic food and drinks, artificial sweeteners, fizzy drinks and anything which you can identify which may be affecting the bladder sensations. 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 yhs-tr.patientexperienceteam@nhs.net.

An answer phone is available out of hours.

Leaflets in alternative languages or formats

If you would like this information in a different format, including braille or easy read, or translated into a different language, please speak to a member of staff in the ward or department providing your care.

Patient Information Leaflets can be accessed via the Trust's Patient Information Leaflet website:
www.yorkhospitals.nhs.uk/your-visit/patient-information-leaflets/

Owner	Sarah Hillery, Lead Nurse Urology
Date first issued	August 2003
Review Date	November 2027
Version	7 (issued December 2024)
Approved by	Urology 2024
Document Reference	PIL 18 v7
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