



involved in your care can give you advice on medical treatments.

Adjusting to a new way of life

How long the pain lasts varies from person to person. Some people may experience pain for a couple of months and it then stops. Other people continue to experience some pain but it becomes much less intense. Bladder pain syndrome may mean adapting to a new way of life, taking your symptoms into consideration. Your relationships, work and hobbies may all be affected. Coming to terms with these changes and making

adjustments to make sure that you can still enjoy life is a difficult process. If you are struggling with this, ask your GP to refer you to a pain-management service.

Further information and help

The International Painful Bladder Foundation
www.painful-bladder.org/

Bladder Health UK
www.bladderhealthuk.org/

Pelvic Pain Support Network
www.pelvicpain.org.uk/

The author: Dr Shona Brown is clinical psychologist with Expect, NHS Lothian’s multidisciplinary pelvic pain service.
An award from The Women’s Fund for Scotland has allowed us to produce the following resources for long-term pelvic pain.

An award from The Women’s Fund for Scotland has allowed us to produce the following resources for long-term pelvic pain.

- **Vulvodynia: Airing Pain** radio programme 87 and accompanying leaflet
- **Bladder Pain Syndrome: Airing Pain** radio programme 88 and accompanying leaflet

Bladder pain syndrome. © Shona Brown. All rights reserved. January 2018.
To be reviewed January 2021.

Edited by Daniel Miele.

Informing the Pain Community

- Living a full life with pain
- Evidence-based treatments and the latest research
- All aspects of pain management

Airing Pain radio programme

podcasts | online

Pain Matters magazine

news | features | opinion

Award-winning research

videos and Navigator Tool

Online community

on HealthUnlocked

Helpline

Call **0300 123 0789**

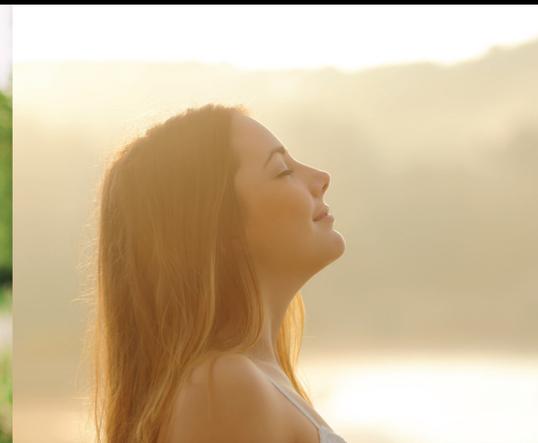
Accredited leaflets

Find out more at painconcern.org.uk

Pain Concern
62-66 Newcraighall Road, Edinburgh EH15 3HS
T: 0300 102 0162
Charity reg. SC023559, Co. Ltd. by guarantee SC546994



Bladder pain syndrome



What is bladder pain syndrome?

Bladder pain syndrome (also known as interstitial cystitis and painful bladder syndrome) results in pelvic pain, and this is often made worse when your bladder is full. If you have bladder pain syndrome you may have to empty your bladder often and may wake during the night to go to the toilet. You may have a strong urge to empty your bladder, and this is often very uncomfortable or painful. You may also find it difficult to wait to go to the toilet. Bladder pain syndrome affects more women than men.

The symptoms are similar to a urinary tract infection (cystitis), but without an infection in the urine. Often people have lots of tests on their bladder. Sometimes they feel that no-one believes they are always in pain, or they feel that doctors think the pain is 'in their head'. We know that bladder pain syndrome is not imagined and that the pain is very real and can be distressing to live with.

How is bladder pain syndrome diagnosed?

Doctors diagnose bladder pain syndrome by asking about your symptoms and carrying out tests on the bladder. Urologists and

urogynaecologists are the medical professionals working in this area. They will try to find out if there is a problem with your bladder that can be treated medically. Bladder diaries, cystoscopy (where a doctor looks inside your bladder using a small camera) and urodynamics (a test to check how well your bladder works) are useful when trying to identify bladder pain syndrome. The tests are also important to make sure there are no other problems with your bladder that could be causing your symptoms.

Why do I have bladder pain syndrome?

The symptoms can begin after repeated urinary tract infections, after an operation or after childbirth. Sometimes bladder pain syndrome starts 'out of the blue', with no obvious trigger. It can get worse over time or start suddenly. Scientists are still trying to find out why some people develop bladder pain syndrome. We do know that it is linked to a problem with the pain system.

We need our body to send pain signals when there is damage that needs attention. However, the pain system can go wrong. Pain does not necessarily mean that there is damage



to the bladder. The problem can be that the nerve fibres in the bladder area have become too sensitive and so send pain signals. This is a problem with the nervous system, so doesn't show up on blood tests, scans, cystoscopy or other medical tests. It does not mean there is nothing wrong, but helps show that there is a problem with pain signalling in the bladder area. Our leaflet **Neuropathic Pain** has more information about the science of the pain system.

What can help?

Learning more about the condition

People find it helpful to learn more about bladder pain syndrome. On our website, you will find a radio programme, **Airing Pain programme 88**, which accompanies this leaflet. The International Painful Bladder Foundation website also has helpful information and links. See the end of this leaflet for contact details.



Diet

Certain food and drink may make your pain worse. It can help to keep a diary for a week or two, noting how strong the pain is (for example, on a scale of 0 to 10, if 0 = no pain and 10 = the worst pain) and what you have had to eat and drink.

Managing stress

Stress does not cause bladder pain syndrome, but when we are stressed our pelvic floor muscles are often tense and this has been shown to be linked to pelvic pain. The chemicals our bodies release when we are stressed (adrenaline and cortisol)

affect the nervous system by turning up the volume of pain signals. Living with bladder pain is life-altering and this can be stressful. Practising a relaxation technique such as progressive muscle relaxation, soothing rhythm breathing, guided imagery or mindfulness meditation can help. Our leaflet **Stress, Pain and Relaxation** gives you more information about managing stress.

Pelvic floor relaxation and physiotherapy

Some people have found it helpful to see a physiotherapist to have their pelvic floor muscles assessed and develop their skills in relaxing these muscles.

Medical treatments

Medication can help lessen symptoms, but there is not one medicine that helps everyone with bladder pain syndrome. Anti-inflammatory medicines can help, and some people report that they have been helped by antispasmodics. There are medicines which act on the nervous system to damp down the oversensitive nerve fibres. The medical professionals