

# Your guide to elmiron® (pentosan polysulfate sodium) and Bladder Pain Syndrome

This leaflet is intended for patients who have been prescribed elmiron®

## Bladder pain syndrome (BPS)

Bladder pain syndrome (BPS) is sometimes called painful bladder syndrome (PBS) or interstitial cystitis (IN-ter-STISH-ul sis-TY-tis) (IC). It is a long-term, painful condition of the bladder that can affect men but is more common in women.

Experts don't know exactly what causes BPS, but many theories have been proposed.

One of these theories suggests that a defect in the lining of the inside of the bladder allows substances in the urine to enter the bladder wall and cause irritation and pain.

## What are the symptoms you may be experiencing?

Symptoms of BPS can feel quite similar to a bladder infection; however, unlike a bladder infection, BPS does not improve with antibiotics and no obvious infection can be identified. It is often described as a feeling of discomfort and pressure in the bladder area that lasts for 6 weeks or more.

These symptoms can be debilitating, frustrating and unpredictable, often vary from person to person and can even change over time in the same individual. The most common symptoms of BPS to look out for are:

- Pelvic or abdominal pain
- Frequent urination (>7 times a day)
- Waking up in the night to go to the toilet
- A constant urge to pass urine, even after emptying the bladder
- Pain during sexual intercourse

## What is elmiron®?

Your healthcare team has prescribed you **elmiron®**

**elmiron®** is a medication used to treat a specific type of bladder pain syndrome (BPS) with two distinct features ('lesions') inside the bladder:

- **Tiny bleeds (glomerulations)**
- **Distinctive lesions/ulcers on the bladder wall (Hunner's lesions)**

BPS with evidence of tiny bleeds or lesions/ulcers on the bladder wall is sometimes referred to as, interstitial cystitis/bladder pain syndrome or IC/BPS for short.

### How does elmiron® work?

**elmiron®** contains the active substance pentosan polysulfate sodium. It is taken orally and passes into the urine and attaches to the lining of the bladder, helping to form a protective layer, to reduce irritation and relieve symptoms over time.

**elmiron®** has been shown to reduce:<sup>1</sup>

- Bladder pain
- The constant urge to pass urine
- The number of times that you need to go to the toilet
- The need to get up in the night to go to the toilet

## What to expect

Everyone is different, so you may notice relief sooner than expected, but even if you do not, it is important to not get disheartened. The important thing is to keep taking your medication as directed by your healthcare team. If you have not experienced symptom improvement after 6 months of taking **elmiron®**, please talk to your healthcare team.

It is worth taking note of symptom changes using a questionnaire, which your healthcare professional may provide you with.

### How do I take elmiron®?

Always take **elmiron®** according to the instructions given to you by your healthcare team, ensuring you read the patient information leaflet <sup>2</sup>.

The recommended dosage of **elmiron®** is one 100 mg capsule, 3 times a day, taken with water at least 1 hour before meals or 2 hours after meals.

If you forget to take **elmiron®**, take your missed dose as soon as you remember or, if it's nearly time for your next dose, skip your missed dose altogether.

The way **elmiron®** repairs the bladder lining is a gradual process, and it may take up to 6 months before you start noticing relief. This is normal.

It is important that you don't stop taking **elmiron®** or reduce your dosage because you are feeling better or because **elmiron®** does not appear to work straight away.

## What does your healthcare team need to know?

Tell your healthcare team if you:

- Are taking anticoagulant therapy, such as warfarin sodium, heparin, high doses of aspirin (usually 300 mg or more), or anti-inflammatory drugs such as ibuprofen
- Could be pregnant or are breastfeeding; **elmiron®** is not recommended during pregnancy or breastfeeding
- Have any liver or kidney problems
- Are having surgery; **elmiron®** is a weak anticoagulant (blood thinner), which may increase bleeding.

## Important safety information

**elmiron®** is generally well tolerated but like all medicines, it may still cause some side effects. Most of these are minor, but if something is bothering you or if anything doesn't feel right, it is important to tell your healthcare team.

The most common side effects that you might experience include:

- **Diarrhoea**
- **Nausea**
- **Upset stomach**
- **Dizziness**
- **Blood in the stool**
- **Headache**
- **Swelling caused by fluid build-up in the body**
- **Hair loss**

Don't panic! It's important to note that **elmiron®** does not cause permanent hair loss, but rather increases the length of time hair follicles are inactive before they re-grow.

In rare cases, eye problems have been reported with **elmiron®** use (especially after long-term use). It is important to tell your healthcare team immediately if you experience visual changes such as reading difficulties and slower adjustment to low or reduced light. Your healthcare team will discuss with you whether your treatment should be continued and how often you should go for an eye test while taking **elmiron®**.

Remember, if you experience any side effects, talk to your healthcare team. This includes any possible side effects not listed in this leaflet.

By reporting side effects, you can help provide more information on the safety of this medicine.

## What else should I know about managing IC/BPS?

To help manage your symptoms, **elmiron®** may be prescribed alone or in combination with other treatments. Your healthcare team will discuss different treatment options with you, and together you will decide on the best treatment plan.

Your healthcare team may also advise lifestyle adjustments to help you manage the symptoms of BPS such as:

- **Avoiding certain foods and drinks known to be bladder irritants.**  
Go to <https://bladderhealthuk.org/> for more information
- **Physiotherapy** – massaging the pelvic floor muscles may help reduce any strain on your bladder
- **Bladder re-training** – where you gradually learn to be able to hold more urine in your bladder before needing to go to the toilet.

## Where can I find more support?

### You are not alone

A support network of family, friends and caregivers may help you through your treatment. In addition, patient advice groups can provide you with more information, help and support. Below is a list of websites for support organisations that you and your caregivers may find helpful.

- <http://bladderhealthuk.org>
- <https://www.ic-network.com>
- <https://painuk.org>

## Adverse event reporting

**Reporting of side effects:** If you experience any side effects, talk to your healthcare team, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at [www.mhra.gov.uk/yellowcard](http://www.mhra.gov.uk/yellowcard). By reporting side effects, you can help provide more information on the safety of this medicine.

### References

1. **elmiron®**. summary of product characteristics
2. **elmiron®**. patient information leaflet

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