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

## Tips for SUCCESSFUI treatment

of bladder pain syndrome for patients taking elmiron<sup>®</sup> (pentosan polysulfate sodium)





This leaflet was created and funded by Consilient Health. elmiron<sup>®</sup> is a registered trademark of bene-Arzneimittel GmbH

## How does elmiron® work?

elmiron<sup>®</sup> contains the active substance pentosan polysulfate sodium. It is taken orally, 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**<sup>®</sup> has been shown to reduce:

- 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

## Follow this advice

#### for the best chances of successful treatment

Step 1: Take elmiron<sup>®</sup> for a minimum of 6 months.

Step 2: Take elmiron<sup>®</sup> 3 times per day with water 1 hour before or 2 hours after food.

#### WHY STEP 1? Take elmiron<sup>®</sup> for a minimum of 6 months.

?

Studies found that in some patients, treatment started to work at 4-5 weeks, and continues to improve symptoms for several months.

Some experts believe that the most important factor in determining the benefit of treatment is the length of time you take the medicine.

#### WHY STEP 2? Take it 3 times per day and take it with water avoiding meal times.



Taking 1 capsule, 3 times per day is necessary for full effectiveness. The medicine needs to accumulate in the body for at least 7 days and requires constant doses to maintain this.

Swallowing the capsules with food can reduce the absorption of the medicine in the intestine. If the medicine isn't absorbed it will pass through your body without working.

## tow do I take elmiron®?

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

The recommended dosage of **elmiron**<sup>®</sup> is one 100 mg capsule, 3 times daily. If you forget to take **elmiron**<sup>®</sup>, take your missed dose as soon as you remember or, if it's nearly time for your next dose, skip your missed dose altogether.

It may take up to 6 months before you start noticing relief however this is normal. It is important that you don't stop taking **elmiron**<sup>®</sup> or reduce your dosage because you are feeling better.

### **Important safety information**

elmiron<sup>®</sup> 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

In rare cases, vision changes have been reported with **elmiron**<sup>®</sup> use (especially after long-term use). It is important to tell your healthcare team immediately if you experience visual changes such as reading difficulties, visual distortions, altered colour vision and/or slower adjustment to low or reduced light.

Have your eyes tested after 6 months of treatment with elmiron<sup>®</sup> and if no problems then after five years of treatment. Should issues be found, annual eye tests are advised. Tell the optician you are taking a medicine that may be associated with maculopathy.

Remember, if you experience any side effects, talk to your healthcare team. 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 https://yellowcard.mhra.gov.uk/. By reporting side effects, you can help provide more information on the safety of this medicine.

#### • Headache

#### • Swelling caused by fluid build-up in the body

• Hair thinning - Don't panic! It's important to note that **elmiron**<sup>®</sup> may cause hair thinning in less than 1 in 10 patients and this is reversible.

# Things you can do to manage bladder pain syndrome (BPS)

Following a few BPS lifestyle tips may help you to take back control. Things that may help improve your symptoms include:

#### • Reducing stress

Anything that helps you to relax, such as exercise or regular warm baths, listening to relaxing music, may help reduce your symptoms, and recent evidence suggests that mindfulness-based techniques, such as meditation, can help.

• Limiting certain foods and drinks

Speak to a Healthcare Professional before trying an elimination diet/exclusion diet. You must find out

## supportive therapies

Some people also find the following supportive therapies helpful:

**Physiotherapy** – for more information, contact the Pelvic Pain Network by scanning the QR code or by visiting: https://www.instagram.com/pelvicpainnetwork/

**Psychological therapy** – to help you cope with your symptoms and their impact on your life, such as Cognitive Behavioural Therapy (CBT). For additional advice contact Bladder Health UK 0121 702 0820 or Bladder and Bowel UK helpline 0161 214 4591.

For local psychological services, scan the QR code or visit: https://www.nhs.uk/service-search/other-health-services/psychology-service/

how foods affect your bladder. An elimination diet is a meal plan that avoids or removes certain foods or ingredients so you can find out what you might be sensitive to. Some patients have noted improvements after avoiding

certain foods or drinks.

The list of foods that have been said to affect BPS is guite long, but not all foods affect all patients in the same way. Examples include, citrus fruits, tomatoes, chocolate, coffee, alcohol and fizzy drinks.

## Other resources

People who join patient support groups:

- have better health outcomes than those who solely rely on medical interventions.
- may learn new ways to deal with their illness from other people's coping strategies.
- will receive support to stay motivated to stick to treatment plans.







#### Below are 2 websites that you and your caregivers may find helpful

#### **Bladder Health UK**



#### bladderhealthuk.org

#### **Bladder & Bowel UK**



#### bbuk.org.uk/?s=interstitial



## Tips for successful treatment of bladder pain syndrome with elmiron®

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#### References

elmiron<sup>®</sup> 100 mg hard capsules, Summary of Product Characteristics, Consilient Health Ltd. Parsons CL & Mulholland SG. J Urol 1987; 138: 513-516. Kanter G et al. Int Urogynecol J. 2016 Nov;27(11):1705-1711. doi: 10.1007/s00192-016-3022-8. Evans RJ. Rev Urol. 2002;4 Suppl 1(Suppl 1):S16-20. PMID: 16986029; PMCID: PMC1476004.

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