

Elmiron: This Common Bladder Pill Is Causing Blindness

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STORY AT-A-GLANCE

- › Interstitial Cystitis (IC) is a chronic bladder condition that may trigger scarring and stiffening of the bladder walls. After decades of use, new information demonstrates a long-term medication, Elmiron, may cause retinal damage mimicking age-related macular degeneration or pattern dystrophy, resulting in blindness
- › Researchers are hopeful that if identified early, the damage may be mitigated; how the damage is triggered is unclear
- › IC causes a frequent urge to urinate, sometimes up to 60 times in a 24-hour period. It also causes pain and pressure in the bladder. Those with IC may also have migraine headaches, irritable bowel syndrome, fibromyalgia, chronic fatigue and/or allergies. Those with pelvic floor dysfunction may find relief with physical therapy
- › Certain foods trigger symptoms in the bladder, as do stress and anxiety since it increases muscle tension. One study found symptom relief with melatonin and another with quercetin; consider using emotional freedom techniques to help reduce stress and muscle tension and to experience pain relief

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Interstitial cystitis (IC) is a chronic bladder condition that may cause scarring and stiffening of the bladder walls. Researchers¹ have found that only 10% of those who suffer from IC are men. In the male population, characteristic symptoms include pelvic pain, dysfunction with urination and chronic prostatitis with pain associated with sexual

activity. Women who have the condition often have chronic pain in their bladder, irritable bowel syndrome and other issues.

In a population-based study, researchers found the median age of onset was 40 years and up to 50% would experience a spontaneous remission ranging from one month to 80 months. Those with IC were twice as likely to have a history of urinary tract infections.

The researchers found the quality of life in those suffering from IC was lower than those of individuals going through chronic dialysis for renal failure. It's estimated more than 1 million in the U.S. suffer from this condition, most of whom are women. To date, there's only one medication approved by the U.S. Food and Drug Administration to treat IC.²

The drug Elmiron was approved for use in October 1996 as a treatment for pain and discomfort associated with the condition.³ Since it has been the cornerstone of treatment for decades, it's estimated hundreds of thousands have used the drug.

Elmiron Increases Risk of Retinal Damage

In 2018, Dr. Nieraj Jain from the Emory Eye Center in Atlanta reported six of his patients had developed changes in the central area of the retina called the macula, which had led to reading difficulties and visual changes the patients experienced in dark conditions.⁴ Six patients underwent genetic testing as part of an inquiry aimed at identifying the reason for the damage, but none was found other than long-term use of Elmiron.

The macula, located in the central area of the retina, is responsible for clear central vision. After a review of the patient's medical history and diagnostic testing, Jain could find nothing explaining the pattern of abnormalities and so raised a warning that long-term use of Elmiron may have damaged his patient's retinas.⁵

Subsequently, three ophthalmologists from Kaiser Permanente did a review of 4.3 million patients in northern California and found nearly 25% of those who had been taking Elmiron exhibited signs of eye damage. The researchers determined the damage caused by toxicity from the medication may have been masquerading as other conditions, such as pattern dystrophy or age-related macular degeneration.⁶

In the 4.3 million patients the team reviewed, they found 140 who had taken an average of 5,000 pills over 15 years. Of those, 91 agreed to an examination and 22 demonstrated clear signs of toxicity. The researchers found the rate of toxicity and damage increased as the dosage the patients took increased.⁷

Dr. Robin Vora is chair of ophthalmology at Kaiser Permanente and lead researcher of the study. He commented on the outcome of treatment for IC using Elmiron:⁸

“It’s unfortunate. You have a patient with a chronic condition like interstitial cystitis, for which there is no cure and no effective treatment. They get put on these medications because it’s thought to have few side effects and few risks, and no one thinks about it again. And year after year, the number of pills they’re taking goes up and up.”

Retinal Damage May Be Reduced if Medication Is Discontinued

If the damage is identified early, researchers are hopeful it may be mitigated when the medication is discontinued.⁹ Vora recommends those taking the medication who have no symptoms and show no signs of retinal toxicity should be screened annually.¹⁰

How the retinal damage is caused by Elmiron is unclear, but Jain’s team suggests a component of the drug may play a role. Researchers from the Cleveland Clinic suggest Elmiron is an antagonist of signaling pathways for fibroblast growth factor.

There is some concern that visual damage may be an unrecognized effect of IC since its presentation is not like any other identified maculopathy. Researchers report that in later stages, toxicity looks like late-stage atrophic age-related macular degeneration, which results in permanent vision loss.

After numerous studies and an FDA citizens petition detailing concerns about retinal damage in those who are using it, Elmiron’s label was changed to include a warning about the eye disease and retinal pigmentary changes.¹¹

Interstitial Cystitis: What Is It and How Is It Treated?

Your bladder is a hollow muscle designed to collect urine excreted from the kidneys before it signals your brain it's time to empty.¹² This communication happens through the pelvic nerves and creates an urge to urinate. Unfortunately, those suffering with IC get the signals mixed up and feel the urge to urinate more frequently.

The condition is also called painful bladder syndrome since it triggers recurring bouts of pain. Sufferers may experience the urge to urinate up to 60 times a day, including during the night. Only half of those with the disorder are able to work full time. Those suffering with IC may also experience migraine headaches, [irritable bowel syndrome](#), fibromyalgia, chronic fatigue syndrome and allergies.

The exact mechanism for the condition is unknown but biopsies have indicated abnormalities in the bladder wall. Lines of research into the trigger are focused on the inner layer of the bladder wall that may allow toxins to leak through or substances that block the normal growth of the cells lining the bladder.

Others have theorized a viral agent may trigger an infection or an autoimmune disorder may be responsible. Since the trigger is unknown, the diagnosis is made by excluding other similar conditions. Testing and treatment are usually done by a urologist or gynecologist to rule out infections, bladder stones, kidney disease, multiple sclerosis and sexually transmitted diseases, among other disorders.

Management of the condition often starts with conservative measures. The most common medication used has been Elmiron, the only drug approved specifically for the treatment of IC. It can take several months to feel an effect, and the effect may only be modest. Other drugs used include painkillers, tricyclic antidepressants to help relax the bladder and antihistamines to block mast cell release.

Trigger Foods and the IC Diet

In addition to medication, management may also include dietary modification, stress reduction and therapy.¹³ The IC Network¹⁴ recommends identifying the foods that trigger your symptoms and irritate your bladder, as dietary modification is a crucial first step in taking charge of your condition and helping protect your bladder.

It may take up to six months to develop a personalized list of foods you know will trigger your symptoms. However, the IC Network offers a starting list of three types of foods that are:

- Well-tolerated by most
- Generally safe but could irritate some bladders
- Should be avoided as they trigger discomfort in many

Some of the most bothersome foods include any type of caffeinated drink, alcohol, citrus, spicy foods and artificial sweeteners. Those that are the least bothersome appear to be most fruit and vegetables, water, milk, meat and eggs.

Interstitial Cystitis Drug-Free Management Options

The Interstitial Cystitis Association¹⁵ recommends those who suffer to be proactive and plan ahead. The sooner a flare-up is treated, the faster it can be resolved. They recommend self-help techniques to reduce irritation in the bladder such as learning self-hypnosis, stress reduction techniques and relaxation techniques.

Some flare-ups are triggered by wearing restrictive clothing such as pantyhose, tight jeans or slimming garments. Some people experience relief with simple strategies at home including:

- Reducing the concentration of urine by drinking more water
- Using a hot pack or cold pack in the perineum area, experimenting to see which works best
- Taking a warm sitz bath with or without Epsom salt

- Relaxing your pelvic muscles by placing your knees to your chest or lying on your back with your legs spread
- If you're not on a salt-restricted diet, having a glass of water mixed with 1 teaspoon of baking soda to help reduce the burning sensation

If you believe you may have a urinary tract infection, seek medical attention quickly as an infection can trigger a flare-up and may be challenging to resolve if it isn't addressed right away. One animal study found melatonin improved symptoms and reduced histological damage in the bladder.¹⁶ Another preliminary study with 17 women and 5 men found oral supplementation with quercetin provided significant improvement.¹⁷

In addition to the health conditions listed above, those with IC may also experience pelvic floor dysfunction. Exercises with a physical therapist focus on core strengthening and relaxation, and can help relieve pain since pain tends to tighten pelvic muscles and increases discomfort during urination.¹⁸

Reducing stress and muscle tension often helps alleviate pain and discomfort, including in those with IC. **Emotional Freedom Techniques (EFT)** are rather effective and may be used in private or public without the fear of side effects.

Sources and References

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