

NewsLetter

VOLUME 3, ISSUE 2 (MARCH 2021)



GLOBAL INTERSTITIAL CYSTITIS,
BLADDER PAIN SOCIETY

“EXPERIENCES AND QUERIES FROM THE OTHER SIDE OF TABLE: FAQ’S FROM PATIENTS”



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As a patient, patient advocate and founder of Interstitial Cystitis India, I often come across a few common questions from the patients. In this article, I would try to answer them.

1) Am I the only person suffering from this disease?

Most newly diagnosed patients feel that they are the only ones diagnosed with this disease. I had also felt the same when I was first diagnosed. However, even though this is considered a rare disease, yet there are many people suffering from this disease in India and abroad.

2) Is this curable?

Unfortunately, there is no cure for this disease. However, the silver lining is that with proper medication, diet and exercise one can go into remission and live a normal life quite easily.

3) Is Indian diet harmful for IC?

Most patients look for information online. Most websites and Facebook forums are maintained by non-Indian people where there is a general consensus that Indian food is harmful for IC. However, the truth is that only spicy food is harmful and not Indian food in general. India is a huge country with varied cuisines. However, most

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people associate Indian cuisine with spicy food because they do not have proper knowledge about our culture and cuisine. The truth is, if you can restrict the amount of garam masla (whole spices of cinnamon, mace, peppercorns, coriander seeds, cumin seeds, and cardamom pods are toasted in a pan to release their aromatic flavors, then ground to a powder), chilli powder, chillies and spicy pickles then Indian food is one of the best diet options for patients. The spices that we put in our food like turmeric, ginger, garlic, cumin, coriander, and asafetida have healing properties and they benefit us. Homemade curd or dahi is a good probiotic and helps patients. As most Indians are vegetarian our diet is generally alkaline and that helps us heal our bladder naturally.

4) **Is roti (handmade flat round wheat bread cooked on a griddle) bad for IC?**

There is a belief that gluten sensitivity is related to IC. However, there is no proper research to prove that gluten causes or flares IC. The people those who have gluten sensitivity is a small percentage. Roti is therefore not harmful for IC. However, if you wish to go for a gluten free option then you can always eat jowar, bajra or corn roti.

5) **Should I go for embedded infection and biofilm testing?**

Lots of misconceptions have been created regarding embedded infection and biofilm testing. Currently there is no evidence that IC is the result of a previously-undetected infection. Long-term antibiotics - the treatment that would be indicated for a bladder infection - have been shown to be ineffective and are specifically not recommended by the American Urological Association. The term "embedded infection" is also scary, but it's actually really common for bacteria to create "biofilms" as they grow.

6) **Should I go for Microgen Testing?**

If you take a Microgen test, you will find bacteria in your urine. Everyone naturally

has levels of these bacteria. The real question is do we see a difference in the bacteria found in patients with IC-like symptoms and people without pain at all? The answer, at least so far, is no. No replicable difference has been shown in the bladder microbiome.

7) **Is Homeopathy and Ayurvedic treatment better for IC?**

If you want to try that is your choice however, there is no evidence that alternative medicine work better for IC. Many patients flare from homeopathic pills due to their alcohol content. Ayurvedic medicine also often causes discomfort.

8) **What exercises help IC?**

Ideally, I would suggest that you get yourself checked by a pelvic floor therapist and do exercises advised by the doctor. However, if you do not have access to any PFT, then you can go for walking or simple yoga stretches like 'happy baby pose', 'downward dog', and 'butterfly' etc. They help strengthen your muscles. However, if you feel that exercise is flaring you then immediately stop.

9) **How to not flare after intercourse?**

Most IC patients feel discomfort during or after sex. However, with a few simple tricks you can enjoy sex. Try to be relaxed, use lubrication, do not rush, go slow, urinate before and after the act, drink water before sex, use a hot or cold pack after the act.

10) **How to lead a normal life with IC?**

IC is not the end of life. It is a difficult disease but with a positive attitude you can lead a normal life. Try to reduce your stress through meditation. Stress is the number one reason for flare-ups, therefore, it is extremely important to keep your stress under control. Follow the IC diet and take your medicines. A healthy lifestyle would keep your symptoms under control and you would be able to enjoy a happy and normal life.



Author

MS. BALAKA BASU

Patient Advocate from India
Founder of ICI

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**GLOBAL INTERSTITIAL CYSTITIS,
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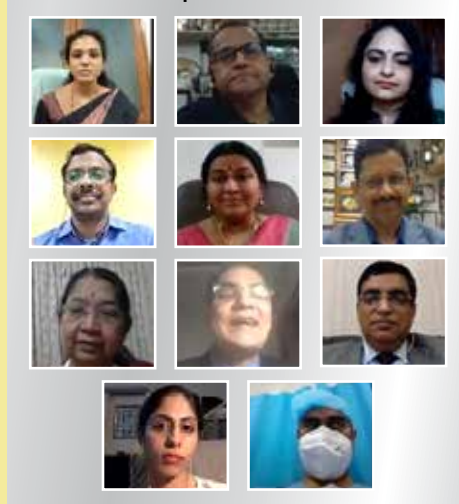
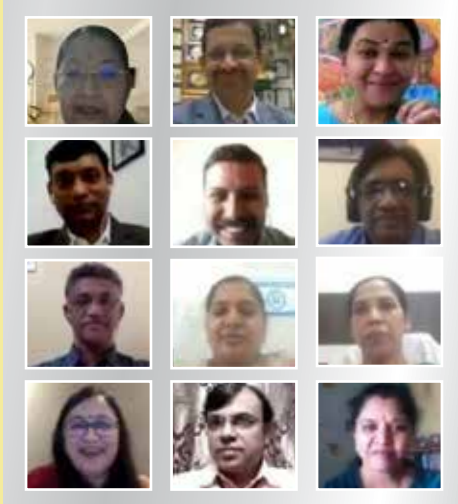
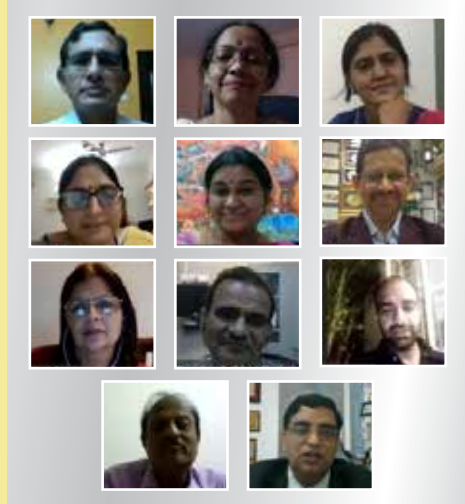
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Date: 16th January 2021
Theme: Pelvic Pain An Enigma
Participants: 220 plus

Date: 24th January 2021
Theme: Bladder Pain A Conundrum
Participants: 170 plus

Date: 27th February 2021
Theme: The Bladder Pain Trio How To Conquer
Participants: 250 plus



Female Pelvic Pain Association (FEPPA)
In association with AICC RCOG NZ
Conducted it's 2nd Virtual Workshop



Theme - Connotations of Pelvic Pain | Participants: 305 plus

