IC Patients Speak: PT and Self-Care

By Mark Toner

For many IC patients, pelvic floor physical therapy and self-care activities ranging from gentle stretches and exercise to breathing and mindfulness can bring significant relief, according to an ICA survey.

“I have tried everything possible for IC, including experimental treatments, and it is the only thing that helped,” one patient who responded to the ICA survey said of pelvic floor physical therapy. “It does not eliminate the pain but significantly reduces it.”

PT as a ‘Lifeline’

Nearly two-thirds (64 percent) of the 143 IC patients who responded to an informal ICA survey on physical therapy and other self-care activities in Fall 2016 were referred to pelvic floor physical therapy by their physician. What’s more, nearly 75 percent of those who tried pelvic floor physical therapy believed it was helpful, according to the survey. While the survey is not statistically valid, the experience of the IC patients who responded confirm what multiple scientific research studies have shown: the effectiveness of pelvic floor physical therapy as a treatment for IC’s symptoms of pain, frequency, and urgency in most (but not all) patients.

Source: ICA survey, n=143, 105

“Physical therapists have been able to reduce pelvic pain when nothing else worked,” one patient said. “They are a lifeline and I have the utmost respect for them.”

Patients said that physical therapy helped with all three of IC’s telltale symptoms—to varying extents. “It helped with the pain mostly (90 percent reduction) and urgency (90 percent reduction), but less with frequency (50 percent reduction),” one said.

Survey respondents also were quick to point out that physical therapy is an important part of a broader IC treatment plan. “A lot of it is a mixture of treatment for IC and physical therapy on top of it to relax the clenched muscles you’re constantly contracting because of being in pain for so long,” one said. “I always say that my 90 percent reduction in IC symptoms was half due to physical therapy and half to diet and lifestyle, because once I combined these, I felt better than I had in years.”

Not all patients who responded to ICA’s survey said they benefitted from pelvic floor physical therapy. Some said the treatments caused pain, particularly at first. Others said they had other symptoms in their bladders that had to be addressed first with instillations and other treatments before beginning physical therapy. And still others said their pelvic floor was intact and not the cause of their symptoms—which jibes with research suggesting that pelvic floor dysfunction contributes to IC symptoms in 80 percent or more—but not all—patients.


**Time to Relief**

The majority of IC patients who responded to ICA’s survey saw improvement in symptoms within a few weeks to a few months of starting physical therapy, as shown in the chart below.

<table>
<thead>
<tr>
<th>Time to Positive Impact on IC Symptoms</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Immediately to a week</td>
<td>12%</td>
</tr>
<tr>
<td>2-6 weeks</td>
<td>44%</td>
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<tr>
<td>2-3 months</td>
<td>36%</td>
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<tr>
<td>6 months</td>
<td>4%</td>
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<tr>
<td>1 year or more</td>
<td>4%</td>
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*Source: ICA survey, n=52*

“About every two years or so, I have a bad flare and will need to see a PT for a few months to get back to a good place. It usually takes two months, once a week, to be good enough to self-manage the chronic condition again,” one said. “I generally go to therapy once a week for a month during a bad flare that includes pelvic and hip pain. I am then pain-free for 3-4 months,” added another. “It took a couple of months to get me on a better path,” a third patient said about returning to treatment after “one of the worse flares of my life.”

Above all, IC patients urge patience. “It takes time—lots and lots of time,” one said. “People with IC have been constricting muscles in places we didn’t know we had, and we have to take all this time to reverse the effects of that. It’s painful, but in a way that you know it will benefit you in the future.”

**Self-Care**

IC patients who responded to ICA’s survey also stressed that physical therapy sessions alone aren’t enough to manage symptoms. As one put it, “my biggest problem is working a very stressful job and being exhausted and falling into a cycle of using PT to put out fires and not really making lasting progress.”

To that end, many of the patients who responded to the ICA survey participate in other self-care activities, including home maintenance exercises recommended by their physical therapists or physicians, regular physical activity, and mindfulness and breathing exercises.

A majority of survey respondents said they did self-care exercises at home, including the kind of stretching activities detailed on p. 12 and in the sidebar at right.

“The at-home techniques were invaluable to continue the healthful feeling and keep stress at bay,” one said. “I practice every morning and at other times,” another said. “Some stretches gave me instant relief.”

One patient urged others to continue these activities even when symptoms abate. “I still do them every morning even since my symptoms are pretty much gone. You have to be faithful, like it or not.”

**Self-Care Approaches**

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home maintenance</td>
<td>86%</td>
</tr>
<tr>
<td>Regular physical activity</td>
<td>55%</td>
</tr>
<tr>
<td>Mindfulness/breathing</td>
<td>58%</td>
</tr>
</tbody>
</table>

*Source: ICA Survey, n=143*

**Home Maintenance Activities**

- Stretching
- Deep breathing
- Yoga poses
- Gentle abdominal/core strengthening exercises
- Biofeedback
- Relaxation
- Massage
- Walking
- Using a large ball
- Dilators
- TENS
- Internal exercises
- Bladder training
- Meditation
- Warm baths
- Correct urination and defecation postures
Roughly one-third of IC patients who responded to ICA's survey also said they took part in mindfulness and breathing exercises. “Mindfulness is as important as stretching,” one said.

Regular physical activity also plays an important role in managing IC, though many of the patients who responded to the ICA survey acknowledged limitations to what they can do given their symptoms and, in many cases, overlapping conditions such as arthritis and chronic fatigue. Still, roughly one-third of survey respondents said they were able to maintain a consistent exercise regimen at least three times a week. “I tire easily, though I am improving,” one said.

Some of the activities IC patients say they do regularly are described in the box above. While some are more strenuous than others, respondents emphasized the importance of knowing their limits and taking care to ensure they don’t aggravate their symptoms. Some discussed walking for short periods of time or “at a relatively slow pace or I wind up in a flare.” Others described taking care to avoid activity that involves long periods of standing, squatting, or jumping, or work on exercise machines that vibrate. One person even said that excessive chlorine in pool water could spark flares.

“It varies from week to week,” one patient said. “Some weeks I jog. Some weeks are so bad I can hardly walk.”

Of course, there always are exceptions. “I row in an eight-person sweep rowing crew competitively!” one survey respondent said.

Mark Toner is editor of ICA Update.