

Newsletter: Meeting Date: 22 November 2016, Edition 7

Speaker Nicole Cozean, PT, DPT, WCS Pelvic floor physical therapist – Subspecialty IC

Author: The Interstitial Cystitis Solution – published October 2016 Topic: "Continuing the Education in Bladder Pain Control"

Notes from Meeting:

"The internet can be a blessing and a curse as it has lots of information but you don't always know where the information is coming from or if it is a reliable source...that's why I wrote "The IC Solution" to try to get all the information needed in one reliable source." This is how Nicole began the support group's presentation.

The following are notes gathered as presented by Nicole.

IC is a pelvic pain condition. If you suffer from pelvic floor dysfunction you need to distinguish- pelvic floor spasm vs incontinence vs pain-patients all are treated differently.

IF diagnosis is a weak pelvic floor with incontinence Kegels may help strengthen. IF diagnosis is pelvic pain or frequency the muscles are already tense a Kegel is the WORST thing you can do. Kegels can send already tense muscle into more spasm. This is why it is important if you are going to seek pelvic floor physical therapy that you find someone who has experience treating pelvic pain. Why? Many therapists deal just issues with pregnancy or prolapse and because if you also have prolapse with IC it could be making symptoms worse- it is so complex.

The state of the IC pelvic floor is hypertonic – too tight. I use internal and external techniques to have the pelvic muscles relax. The muscles need to relax for a day or any period of time- key is to get pelvic floor to recognize a new normal – the pelvic floor is never fully relaxed – there is a delicate balance between normal resting tone without fight or flight mode. There is a need to break the pattern and habit of pelvic floor tightening.

Yes, Diet and pelvic floor may be related; food sensitive symptoms are present when symptoms get worse with food or drink.

I see 2 types of IC patients. 1. Overwhelmed- has read a lot or not -is frozen in fear and doesn't know what to do. 2. Hyper focused - taking notes, tagging things, starring items you read, try too many things not knowing what is working – this can cause anxiety.

I try to focus the patient by having them answer, what are my 3 biggest symptoms, 4 things I can do to move forward, where should I start for me?

The symptoms are different in almost every IC patient, each has very individualized urinary and pain symptoms. Symptoms that can be sign of IC that are not recognized are low back pain, hip or groin pain, pain with intercourse, urinary urgency frequency, and constipation. It is Very important to use a symptom log-I encourage my patients to use the symptom log in my book so they can track day to day month to month changes or progress and answer question like - what is bugging me – what is impacting my life the most- they can also rate symptoms and track changes over varying degrees of time. A symptom log is a great way to check in with self – the longer IC goes on the harder it is to see change. A symptom log can make changes apparent. A log is valuable to track what is working and what isn't – look back 2 week vs 2 months and you may notice change i.e. 2 months ago up 6x a night last night 2x a night. After review of the symptom log you can ask yourself what is biggest impact on your life – 3 things or symptoms- work on this first.

Question from group – is stress incontinence common?

Answer- if a patient has this symptom we have to get to bottom of why. I encourage patients to think – all things related to IC may be hard to determine – example: you may think incontinence for your age is normal - it isn't- urinary leaks may be from over tight muscles, maybe IC – but an IC patent may not ever think to put incontinence on a list of IC symptoms so it may not be conventionally thought to be an IC symptom. Pressure could be bladder pro lapse or IC or both.

Question- is urinary retention related to IC?

Answer-The pelvic floor has to relax and the bladder contract this has to happen in a coordinated fashion to enable urination — with IC the bladder cannot fully relax or contract — bladder may not have fully emptied — so you don't fully urinate this may be related to pelvic floor muscles or the bladder itself. It is important to know which because treatments are different.

With IC when you are urinating don't stop and go- urinating is a complicated process – when you stop and go you are sending mixed signals to your brain and muscles- relax – no don't- relax - no don't- that message confuses your bladder and brain. It is not strengthening muscles. This can also send muscles into spasm and also may teach your brain to send you a false urge when your bladder not completely full.

Question- When I pee I find if I lean forward I go more- Why?

Answer- If pelvic floor is not relaxing fully this will press out urine — may mean you are not in best position to urinate and muscles cannot fully relax — squatty potty may help to get full void.

On to bladder retraining technique

Urgency may be a false urge – you may be able to hold it – watch fluid intake. If you hold when pain is present with bladder filling you perpetuate the pain symptom if you don't void. You have to figure out why it is painful. Get rid of pain first then retrain the bladder. You create 15 drops of urine per minute, 300 to 400 ml considered normal void, if normal you can walk around with 150ml in bladder and not even know per Dr. Davis.

Knowledge is power

Urinary urge has peak and valley. When have urge to urinate sit in a chair, calm yourself, let urge ride and go down a tad to take control of urge – first time may last two minutes then next time 2 min and 30 sec...and so on work up to being able to hold longer and control the urge.

With IC you can have pain with bladder filling, in the vagina, and in in urethra- IC has painful signals with things that aren't normal – for example when you walk into a spider web it's all over you ...you brush it off but if something else brushes you... you still think the spider web is on you – this is hypersensitivity. There is a cycle of pain that has to be broken – is it diet, or is it pelvic floor muscles – what are the reasons for the hypersensitivity and why is the patient is in this cycle?

Statement from group – try ice pack to fall asleep- it helps

IC is not just about the bladder- symptoms can be the bladder and/or urethra and the pelvic floor is the setting involved every time you urinate.

Pelvic floor can mimic every symptom of IC. The pelvic floor goes from pubic bone to tail bone.

If muscles are in spasm and mad – try to get muscles to calm down – try to figure out why is this muscle holding onto spasm for dear life- can be tailbone alignment or pelvic bone alignment pubic bone alignment. There are bones, muscles and ligaments that need to be restored so that they are no longer part of painful symptoms. We need our pelvic floor if we didn't have it things would fall on floor, there are 5 main muscles. Pain can be from sitting on pelvic floor i.e.— sitting a long time can irritate the pelvic floor — this may be a sign that the pelvic floor may be involved.

Question- Are Botox injections helpful?

Answer-It is reported that Botox can helpful to relax the bladder allowing it to fill fully – but Botox is not the first line of therapy. if you have tried other therapies and failed Botox may help

I have a blog pelvic sanity – check it out. In studies it has been found some patients will improve 40 to 50 % over 10 pelvic floor physical therapy visits 1 time a week – *Nicole sees patients for 1 hour. She thinks this amount of time is crucial to promote recovery.*

External muscles can influence the way the bladder works -

Inner thigh muscles – the bladder can refer pain to the inner thigh muscles and present as pain on inner thigh-this can be easily reversed and the reflex calmed down – by calming down the inner thigh this can help the bladder. Calves – stretch work can calm down bladder. There is a therapy called tibial nerve stimulation- PTNS. This is where symptom log helps determine where treatment should go. Abdomen – put finger in belly button things should be pliable and loose – can have scar tissue that impeding movement for example from past surgery. Posture can effect bladder – if you are slouched and slumped this puts pressure on the bladder- pain on pelvic floor can cause low back pain need to work on sitting properly- if you sit a long time this can compress bladder and when you stand up you experience urge right away. You need to learn proper stretches – this can ease things –this should be easy to do. Again, this is why tracking symptoms is so important so you can know there has been change

Statement from group – daughter has started therapy they are teaching her to use a probe and do exercises to loosen pelvic floor muscles – it's weird.

Answer- it is probably a crystal wand- this is used for self-treatment- it can be like a knot or charley horse in the pelvic floor — when you have a knot or charley horse you rub it, push on it , stretch it — pelvic floor muscles that need physical therapy are hidden the curved crystal wand allows you reach angry muscles. And it's not weird

In book "The Interstitial Cystitis Solution" on page 138, there is pelvic floor mapping this is how Nicole assesses pelvic floor treatment for patients.

Keep in mind not all pain might be coming from your bladder. Some may think learning this is an overwhelming thought. I think it is hopeful-knots in muscles can be rubbed out. There are plenty of things you can do whether you have had IC for 20 years or 2 hours to affect change.

Need to look at whole picture – emotional mental stress is part of that. When first symptoms appear there is usually some sort of stressor. IC been called "headache in the pelvis" – we hold stress in pelvis this creates pelvic floor pain. You cannot ignore the emotional component of ic; this doesn't mean you are weaker it mean this sucks and you have to address this component- all components have to be healed when you have IC.

Suggestion is to try yoga and deep breathing. We don't need permission to lean about our bodies. There is a mind body connection. Stress may be part of our life but it doesn't mean symptoms don't exist on physical level.

Regarding treatment, Insurance for IC can be an issue, Males are treated rectally, RAND study chronic prostatitis probably IC but that is a whole other topic. Need to create stretching plan- handouts given. Need a plan when get in flare — handout given. Has found 86% IC food sensitive, clean eating is important fresh and preservative free.

Final thoughts-

No matter how long you have had IC there are things you can still do that can help you. Wherever you are there is always room for improvement – wherever you are EVALUATE.

Taking 1st step now may mean going back and starting over.

Set goals – whether it is playing with grandkids or being able to work or being able to drive – then make a plan to get there – take action – take ownership- of your part in this

Focus on moving forward if we always look in the rear view mirror we never get anywhere- we need to see where we were but need to focus on moving forward

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