

When Sex Hurts: Intimacy & Interstitial Cystitis

*Why sexual relations can cause pain and what you can do
to have a satisfying sexual relationship.*

**Featuring Dr. Christopher Jayne, The Center for Women's Sexual Health
Moderated by Jill Osborne, President - IC Network
Date: May 2, 2006**

Jill Osborne - Welcome to the inaugural guest lecture for the 2006 IC & PBS On-Line Patient Conference, the only free lecture series available to interstitial cystitis and painful bladder patients on the web. Our goal is to bring the worlds best researchers, clinicians and activists directly into the homes and offices of patients who are unable to travel and/or afford to attend a national or regional conference. Indeed, most patients stay home and hope to read transcripts or watch DVD's of the various IC events. The internet, however, changes this dynamic. We can now bring the conference directly to thousands of patients at one time. This, of course, would not happen without our generous sponsors, including: [Akpharma \(Makers of Prelief\)](#), [Desert Harvest](#), (Makers of Desert Harvest Aloe) & [Algonot, LLC](#) (Makers of Algonot & Cystoprotek). We thank them for their support and encouragement of IC patients throughout the world.

Tonight we welcome Dr. Christopher Jayne, founder of [The Center for Women's Sexual Health](#), located at The Woman's Hospital of Texas in The Texas Medical Center in Houston. Dr Jayne obtained a Doctor of Medicine from the State University of New York at Buffalo School of Medicine where he graduated with Honors. He completed his Internship at University Hospital Syracuse Health Science Center in New York residency training at Baylor College of Medicine in Houston Texas. While in the US Air Force, he served as a staff Obstetrician and Gynecologist and was promoted to the rank of Major.

A Clinical Instructor for the Department of Obstetrics and Gynecology at Baylor, Dr. Jayne is a Medical Advisory Board Member of ICU-Texas. He is certified by the American Board of Obstetrics and Gynecology and is a certified member of the American Association of Sex Educators Counselors and Therapists.

Dr. Jayne gets rave reviews from clinicians and patients for his dedication in helping understand how IC, PBS (painful bladder syndrome) and pelvic pain syndromes affect our sexual health. He's here tonight to share his thoughts on intimacy, sexuality and IC and will be taking questions but, before we go there, let's give him a chance to say Hi and introduce himself!

DR. JAYNE - It's an honor to be involved in this discussion this evening and thank you very much for your organization, the Interstitial Cystitis Network, and ICU Texas for involving me in this project and topic!

JILL OSBORNE - The hot topic at any support group meeting is sexuality and IC. There is no doubt that some IC patients struggle with discomfort either before or during intimacy. Can you tell us why that happens??

DR. JAYNE - For women, it's about proximity. The bladder sits on top of the vagina, cervix and the lower uterine segment. During vaginal intercourse and penetration, there is a physical displacement (movement) of the vagina, cervix and uterus. Therefore, the bladder is also being moved. **It's this movement that can make it hurt.** In addition, many patients with IC have secondary pain due to pelvic floor muscle dysfunction (aka muscle tension). With vaginal penetration, pelvic floor muscles are strained and this can also lead to pain.

JILL OSBORNE - Men with IC often experience intense pain at the moment of orgasm whereas women with IC often find that their worst pain occurs hours after sexual relations. Do you find that women struggle more with discomfort during sex or after sex??

DR. JAYNE - I think that both of those mechanisms can be explained with one answer. The reason women experience pain after sex and men experience pain during orgasm is because of the muscle component. Pelvic floor muscle spasm and dysfunction plays a significant role in the pain syndrome of interstitial cystitis. When a man has an orgasm all of his pelvic muscles intensely flex at one time and this contributes to the pain for men. Women are having activation and movement of their pelvic floor muscles during intercourse but it's not as intense as when a man experiences orgasm. However, it is longer lasting. So, these women are having a delayed response of pelvic pain because their muscles are continuing to contract after sex. Vaginal penetration can provoke symptoms.

JILL OSBORNE - Have you been able to successfully help IC patients have a comfortable, normal sex life again?

DR. JAYNE - Yes. That said, every patient has their own sense of what is normal to them. It's a two-part treatment plan. We first must educate both the IC patient and her partner on various aspects of sex and sexuality. We also have to optimize their IC treatment plan. When a patient begins to respond to their IC treatments and their bladder begins to improve, he or she can then try sex again, but we're going to try slowly, gently and with some different expectations. Communication is going to be paramount between the partners.

Patients with chronic medical conditions may have to redefine what is a normal sex life. Each culture and each individual has their own understanding of what sexuality is and that changes over time as each person matures. Also events in our lives can change and impact our sexuality. So, each person may develop different expectations, especially when something like IC or another chronic condition occurs. Interstitial cystitis is like a freight train. Because of the pain component, it can really change what you expect with your normal, daily sex life.

JILL OSBORNE - One of the challenges with IC is that our partners are often devastated that they have "hurt" us through the sexual act. They, naturally, may become afraid to touch us for fear of hurting us. The IC patient then wonders why their partner doesn't ask us for sex and get their feelings hurt. It becomes a stalemate . As you said, it's about communication and making sure that there are clear lines of communication open between us and that we talk about it.

DR. JAYNE - I agree. When you talk about sexual activity between couples everyone can have a different understanding of what sex is. An IC patient might be unable to have vaginal penetration but you have to remember that there are OTHER things that you can do that will also be sexually satisfying at least on a short term basis.

The goal of a woman's sexual response is satisfaction. Satisfaction is defined as a sense of love, commitment, being honored, cherished, respected, both sexually and globally in the relationship. Nowhere in that statement did I mention vaginal intercourse.

JILL OSBORNE - Let's assume then that a patient is starting to respond to their IC therapies and they are hoping to start sexual relations again. How would you suggest that they proceed??

DR. JAYNE - Slowly! If you're concerned if penetration is going to hurt badly or if your partner might get too enthusiastic, it can be useful for you, first, to determine what is comfortable for you, perhaps by using a sexual aid such as a [vibrator](#). You can also use a vaginal dilator. The benefit of vaginal dilators is that they come in various sizes from very small to large. The bad thing about the vaginal dilators is that they are kind of sterile equipment. A vibrator can give you more realism. In addition, vibrators are really helpful because they can be helpful reducing pelvic floor muscle tension.

JILL OSBORNE - What about lubrication??

DR. JAYNE - Certainly any pain disorder in the pelvis can reduce your overall level of sexual arousal, thus reducing your natural lubrication. If improving the pain is still not helping with your natural vaginal lubrication, we want to rule out other physiological causes of dryness, such as a hormonal problem or a relative estrogen deficiency for a patient on the oral birth control pill. You need to maximize estrogen to the vagina to maximize arousal. Certainly [lubricants](#) can help. Any

water based lubricant, whether it's Astroglide, Slippery Stuff or similar ones can be helpful but each patient has to determine what their body can tolerate. I would use one that's specifically made for sexual activity rather than something found in the kitchen like vaseline, crisco... and the like!!!

JILL OSBORNE - What if someone can't stand a finger or tampon inside. Is there any type of topical anesthetic that can help??

DR. JAYNE - For any patient who experiences extreme discomfort with a finger or a tampon, it is almost always pelvic floor muscle tension. Nine times out of ten this is the primary cause of that complaint. In this case, physical therapy and muscle relaxation IS THE PRIMARY TREATMENT. Forcing it is not a good idea.

If the patient does not have access to a physical therapy department to treat this pelvic floor dysfunction, the patient can try using a vibrator both externally and internally to massage and relax the pelvic floor muscle. You don't necessarily have to use a vaginal vibrator. You could use a vibrator for your neck that you could put on your perineum or your lower abdomen to help relax the pelvic floor muscles.

Certainly, placing a vaginal vibrator internally will allow you to specifically massage those tender muscles but not everyone has one. Just remember that you have to relax those muscles.

Thus, in this extreme case, I do not think that anesthetic jellies will work because none of them will absorb into the muscles where it's needed. If a PT department isn't available, the patient can have a pudendal nerve block and Botox injections to the pelvic floor muscles by a gynecologist or a urologist.

JILL OSBORNE - What about positions. Are there some positions that are less traumatic to the pelvic floor muscles??

DR. JAYNE - Any vaginal penetration is going to affect the pelvic floor muscles and displace the bladder. Thus you need to experiment to find that which is the most comfortable for you.

JILL OSBORNE - Can we get more detail on how to use the vibrator internally and how often?

DR. JAYNE - Let's talk about sizing for a moment. When you pick a vibrator, don't pick the biggest ones out there. A good rule would be to use the vibrator that takes a double A battery because, obviously, it's not going to be a huge device. If it uses C or D battery... it's probably too large.

If you've never used a vibrator before, the muscles most commonly involved in the pain of IC are located at the bottom of the vagina and right above the rectum and just to the side of the rectum. So, as you are putting it into your vagina, GENTLY push it down towards your rectum and from side to side to massage those muscles. If you can do that, for say, ten minutes at a time, daily, that would be a good starting point. Of course if ten minutes hurts, do it less. There might be some pain but it shouldn't be horrible pain. You don't want to traumatize it so much that the muscles will go back into spasm but a little discomfort is to be expected and hopefully with a modest use of a vibrator, this can be addressed.

JILL OSBORNE - One patient says that her pain occurs right at penetration and feels like needles.

DR. JAYNE - I don't want to oversimplify and say that all pain is coming from muscles. Nine times out of ten, it does come from the muscle but in 10% of cases, it can also be referred pain from the bladder. For these patients we will try a bladder anesthetic (i.e. a marcaine, lidocaine instillation into the bladder). Patients will be asked to hold it in the bladder for half an hour and then they'll go home.

That sensation of a bee sting, needles or heat can be muscle pain but, getting back to my previous example, for the patient who has a bladder anesthetic instillation, we will instruct them to have sex and it's usually comfortable for them. For these patients, they are able to have sex pain free.

JILL OSBORNE - One of our members asks "If lidocaine can be helpful at the opening of the bladder and the vagina, can it also help reduce penetration pain?"

DR. JAYNE - As I said before, it's probably not going to help because it's not going to get deeper into the muscles to help with that muscle tension and pain.

JILL OSBORNE - Another asks "Does that mean that patient should have an instillation prior to sex each time or can we do it ourselves?"

DR. JAYNE - Patients can be taught self instillations.

JILL OSBORNE - Dianne asks "What's the best way to treat vaginal pain that occurs days after penetration?? Would the vibrator help too?"

DR. JAYNE - Use techniques that help muscles relax. Yes, a vibrator can help.

JILL OSBORNE - Another asks "How long will an anesthetic instillation last??"

DR. JAYNE - Every patient is different. Some may have a few hours or relief and some longer. Dr. Moldwin has looked at the bladder anesthetic cocktail as a treatment for IC. He has shown that patients have been pain free for days, even weeks. This is a viable treatment for patients that might be able to be done routinely in the office on a weekly basis.

JILL OSBORNE - What do you feel about the use of muscle relaxant medications?

DR. JAYNE - I certainly do use muscle relaxants for patients with a refractory muscle spasm, such as Flexeril. Patients can be put on a two week course of treatment (i.e. flexeril 5mg three times a day for two weeks) in conjunction with their physical therapy.

JILL OSBORNE - Does insurance cover bladder anesthetic treatments?

DR. JAYNE - In the office, yes. We have standard codes for reimbursement. If its used at home, however, it might not be reimbursable.

JILL OSBORNE - Maureen asks "Isn't an orgasm itself going to produce muscle spasm?"

DR. JAYNE - This is something that the patient has to determine. Not every woman has to have an orgasm to be sexually satisfied. You may find that until your treatments have improved with your IC, you may want to hold off on having an orgasm.

JILL OSBORNE - What about the patient who has just turned off their sexual identity completely because they fear the pain. What would you say to them??"

DR. JAYNE - Everybody has to define sexuality for themselves. It might not need to include vaginal intercourse. There are other things that you can do to be sexually intimate without having vaginal penetration, such as oral sex or mutual masturbation. These are can be very sexually fulfilling.

Remember that a hug will not cause vaginal pain. A kiss will not cause vaginal pain. There are things that you can do to feel loved and comforted and helpful. Most importantly, the future is bright... new therapies are under development right now!

JILL OSBORNE - katz asks "Can ice can help after sex?"

DR. JAYNE - Like any muscle injury, ice can be helpful and in the case of muscle pain after sex, it might be helpful. Some patients have used a condom filled with water that is then kept cool in a refrigerator. This can then be placed on the perineum or internally to help reduce some of that discomfort. Some patients may also use ice in their vagina, which will melt relatively quickly.

JILL OSBORNE - Angela asks "Can recommend any books to help patients with this??"

DR. JAYNE - The Berman book "For Women Only" is a best seller ... and short of that.. I don't have one that I would recommend.

(The [ICN Shop](#) carries several books and DVD's on sexuality, including: *The Ultimate Guide to Sex and Disability* and *The Joy of Erotic Massage*.)

JILL OSBORNE - One patient says that she's having trouble emptying her bladder after sex. Any suggestions?

DR. JAYNE - Try waiting about 30 minutes to give the muscle time to relax. You can also try some of the simple strategies like running water or placing your hand in warm water to help start that off.

JILL OSBORNE - One patient asks "Is it physically or mentally unhealthy to go without sex??"

DR. JAYNE - Being sexually fit is important and it's a use it or lose it phenomenon. The lack of sex can cause sexual dysfunction. So, if you don't have a partner, then self stimulation is paramount. Maintain your sexual fitness!

JILL OSBORNE - One patient asks "Why does a bladder that you've just emptied give you a sensation of being full again during sex?"

DR. JAYNE - Because the bladder is being manipulated or moved around.

JILL OSBORNE - One patient asks if pain is normal during intercourse.

DR. JAYNE - Pain is not normal but it can be a regular occurrence for an IC patient. Loss of urine during sex is NOT NORMAL and should be investigated

JILL OSBORNE - How can we help our partners understand our sexual limitations or experience better?

DR. JAYNE - Communication is what it's all about.

(1) For the IC patient, be honest with your partner about how you're feeling that day. Let them know if you're having a good or a bad day. Don't make them try to read your mind. If you make them guess in the area of sex, they normally guess wrong.

(2) Be willing to learn about what is comfortable for you. If your partner wants to have sex, and you're not ready for vaginal penetration, be creative and/or willing to consider something that can pleasure your partner.

(3) For the spouse without IC, remember that a hug can be healing. If your partner can't have sex tonight, that doesn't mean that they are saying that they don't love you. What they are saying is that right now, at that moment, their body is hurting but their heart is willing.

IC support groups are also a great place to meet other couples so that you can see that you are not alone and that the men can see that it isn't just happening to them. And remember too that men with IC may have wives without IC and they also need the support. So, find a support group near you and go!! It's a great resource!

JILL OSBORNE - Thank you Dr. Jayne! We are so grateful for the gift of your time and for your advocacy for IC patients who struggle with intimacy!

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