



GLOBAL INTERSTITIAL CYSTITIS, BLADDER PAIN SOCIETY

NEWSLETTER

LIVING WITH INTERSTITIAL CYSTITIS AND SEXUAL DYSFUNCTION



Sexual dysfunction in a patient with IC can be disabling, depressing, demoralising and devastating. The worst part to this entire suffering is that besides the patient, the partner suffers too. The narrative below beautifully sums up the feelings of such a couple:

"They've been together for years and his wife now has IC. He so wants to love her, but he's afraid to try. The last time they made love, it had hurt her for days. And so, he turns away with regret in his eyes because he'd rather do anything than hurt her. And she looks to him with sadness in hers, wondering why he doesn't try anymore."

To cope with such frustration and disability, the I C Network has come out with 14 rules for a successful, intimate relationship.

1. Leave guilt and rejection behind you.
2. Put your fears in context.
3. Take slow steps as you try again.
4. Don't doubt the presence of pain.
5. Have Faith in Your Love for Each Other.
6. Your sex life before IC may determine your sex life after IC.
7. Intimacy doesn't always mean intercourse.
8. Develop an appreciation for "outercourse".
9. Cleanliness Counts.
10. Think LUBRICATION.
11. Trying various sexual positions.
12. Use Contraception When Appropriate.
13. Establish an "after sex" routine.
14. It begins and ends with clear communication.



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Rule #1: Leave Guilt and Rejection Behind You

Marriages are partnerships of love, care and affection. Illness and accidents should not be the one to take down this partnership. It can happen to either of the partner. If a partner is in an accident or develops an illness, their spouse doesn't stop loving them or caring for them. The same should be the case with patients with IC. They should stop being harsh on themselves. They should stop feeling worthless and stop letting that feeling of not being capable of being loved creep in. And worse still never stop trying. Leave the guilt behind and let your partner know about the pain and discuss alternatives. There is always a way out. Stop being a martyr.

Rule #2: Put your fears in context

"Sex was painful the last time I did it" or "I don't want to inflict pain to her by indulging in sexual intercourse; I love her too much" is a common fear amongst couples with IC. Hence it is important that both the partners have a guilt free discussion about their fears and to develop a realistic plan for the way forward. It is not the romance which should be kicked out from the life but the fear. New set of rules needs to be drawn for a new kind of sex life. Who knows this new and improved sex life might be better than what was ever imagined before.

Rule #3: Take slow steps as you try again

Imagine someone back from the hospital after recovering from an accident. Would he or she jump straight in for an intimate sexual encounter? Take things slowly. The sexual activity may come slowly, or rather very slowly at first. One is not expected to dive right in, the first night afterwards, and have wild, glorious, athletic sex that lasts for hours. Sexual intercourse may be out for some time but that should not be the case with love, other forms of tenderness and arousal. The key is taking small steps at a time and keep trying new things. Keep exploring and one never knows what will be discovered next.

Rule #4: Don't doubt the presence of pain

Pain is the most common symptom in a patient of IC with sexual dysfunction. Pain may be triggered by various actions with intercourse being just one of them. However, the more important thing than the pain is your understanding of this pain. One would know what and how the pain is triggered, and the answer is to avoid or circumvent those trigger mechanisms. It is important to also understand that some days, the pain may prevent the sexual intercourse. However, despite this, there are ways and means to enjoy those intimate moments. If you stop trying, you'll never know.

Rule #5: Have Faith in Your Love for Each Other

The presence of pain and chronic illness casts uncertainty on various portions of our lives but it does not change the love and bond we share with our partners. When we say "no, I can't do this tonight," we're not saying that we don't love our partners. We are saying that right now, just at this very moment, our body isn't strong enough to do it. Always have faith and trust in your love for each other.

Rule #6: Your sex life before IC may determine your sex life after IC

Can we blame IC on the collapse of a relationship? Can we blame IC on our inability to enjoy intimacy? It has been demonstrated that women who reported high levels of sexual satisfaction prior to developing IC reported high levels of sexual satisfaction even after IC. In addition, it has also been seen that women who scored high on sexual communication, range of sexual experiences, positive mood and drive also reported high levels of satisfaction after the onset of IC. Basically, if you are a good communicator about sex and if you were willing to explore a variety of sexual experiences, then you have a much better chance of having a good sexual life after IC. And, if not, take a moment to learn them. Communication, experimentation and optimism are the common factors of sexual success.

Rule #7: Intimacy doesn't always mean intercourse

Intimacy is an essential component of relationships and IC patients are often interested in exploring alternatives. An interesting anecdote underscores the importance of alternatives. There was a war veteran who had a very satisfying sexual relationship with his partner. But to everyone's surprise he had lost most of his penis in a war injury. How could a man without a penis have sex life that other men envied? The answer was Outercourse. He and his partner practiced outercourse and tantric sex which means that, in their case, their goal was to caress and stroke their partner to that point right before orgasm. The goal was to keep the partner there for an hour or so with or without intercourse. Clearly, sex does not have to involve deep thrusting and intercourse to be satisfying and, in this case, this couple used "tantric sex" as a satisfying alternative.



Rule #8: Develop an appreciation for “outercourse.” It’s wonderful too

A research study completed by Duke University found that only 35% of the respondents reported pain with foreplay or orgasm. This suggests that 65% of patients with IC could engage, comfortably, with foreplay. Given the fact that there will be days when penetration is difficult, outercourse (stroking, arousal, touching, caressing) may be a wonderful option. These are viable, reliable and fulfilling additions to normal intercourse. Rather than seeking orgasm quickly, tantric sex focuses on bringing your partner to the point just before orgasm and then extending that point for longer periods of time. If orgasm happens, that’s fine. If it doesn’t happen, that’s okay too. In tantric sex, the gentlest of movements can become thoroughly arousing and it is a viable option during those moments when IC makes penetration difficult.

Rule #9: Cleanliness Counts

Having a shorter urethra predisposes women to development of UTI. “Honeymoon cystitis” is a classical example of intercourse leading to infection. Hence cleanliness before sex cannot be overstressed. Cleaning the perineum prior to sex should be a regular practice. And if at all possible, make showering together part of your foreplay. Similarly, cleanliness for the male partner is equally important. The cleaning should not be limited to the penis and the foreskin, but a proper hand hygiene and nail trimming should be incorporated as an essential routine. Anal intercourse always increases the risk for infection. Extreme care cannot be overemphasized. Always wash fingers, hands, body parts and/or vibrators that may enter the rectum, before use on any other part of the body.

Rule #10: Think LUBRICATION

Vaginal mucosa is a sensitive area. The friction due to any type of sexual activity can inflame these sensitive tissues if arousal isn’t complete or if there isn’t enough lubrication. Lubrication is an essential tool so that vulva and vagina aren’t abraded and bruised. Use of lubricant during these sexual acts should not be considered a taboo.

Rule #11: Trying various sexual positions

Pain may differ with Sexual positions, with some positions being comfortable while some evoking intense pain. Hence it is essential that the patient should explore different positions and narrow down to continuing with those which seem to be painless. The spoon position has been lauded as good option for women. Other positions can include: the woman on top, the woman astride the man in a chair, or from behind. Go ahead and explore. After all Kamasutra has hundreds of positions and all that is required is a lust for adventure.

GIBS ON THE GO

WEBINAR

GIBS has successfully conducted WEBINARS on IC/BPS with

Nepal Association of Urological Surgeons NAUS-GIBS Live Webinar

Date: 11th June 2020

Topic: IC/BPS

Participants: 230 Plus



Dr. Ragini & GIBS Webinar with ICOG and MOHOGS

Date: 18th June 2020

Topic: IC/BPS & Non – Contraceptive use of
Oral Contraceptive Pills

Participants: 250 Plus

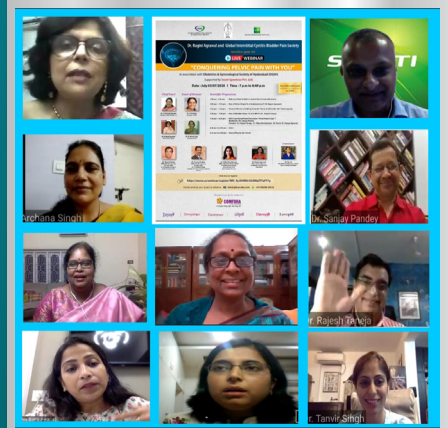


Dr. Ragini & GIBS Webinar with Obs and Gyn Society of Hyderabad (OGSH)

Date: 3rd July 2020

Topic: Conquering Pelvic Pain with you

Participants: 330 Plus



**GLOBAL INTERSTITIAL CYSTITIS,
BLADDER PAIN SOCIETY**

VOLUME 2, ISSUE 4 (JULY 2020)

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Rule #12: Use Contraception When Appropriate

Some IC patients and spouses have anecdotally reported that some creams and spermicides are irritants to both the vagina and the tip of the penis. Hence the three logical rules to be followed for contraception are: (1) If it's comfortable and you are healthy, use it. (2) If you develop strange aches and pains coincidentally, check it out. (3) If it hurts, change it.

Rule #13: Establish an "after sex" routine

Some believe that the first fifteen minutes after sex are when you, the IC patient, can do the most good to prevent infection and reduce inflammation. Most women have been told that they should urinate after sex to expel any possible bacteria that may have been introduced to the bladder during sex. However, this hasn't been proven to eliminate possible infection and/or inflammation. It is a good practice to rinse the area with cool or cold water after the intercourse. This can help soothe the tissues and reduce possible inflammation. Some find cold or heat packs helpful, while others use small, finger shaped balloons filled with water and frozen to be inserted briefly into the vagina after sex to ease the burn or inflammation. The choices can be more, but the idea is to inculcate the practice as a routine.

Divorcing that underwear may also work wonders. It has also been suggested that lying in the bed sans the underwear for some time after the sexual act may be helpful.

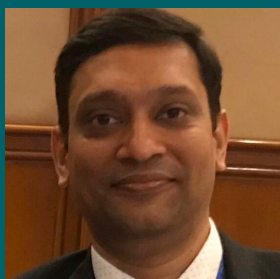
The use of muscle relaxants can be used to reduce muscle spasms. Analgesic vaginal suppositories can also be very helpful in some cases.

Rule #14: It begins and ends with clear communication

During sex, each partner should listen to the cues of the other. "Ouch" or "No" should trigger a pull back, slow down or termination depending on the situation. The important thing is to respect these call signs. If it hurts, try something else. Be creative. Don't take pain personally. It says nothing about your love for each other.

Despite all efforts if you feel that your partner is unfit for sexual activity, kiss them, give them a hug and remind them that your love is steadfast. This will make an everlasting bond.

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Congratulations

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An article by Dr. Amit Agarwal published in Urological Society of India

Topic of Article - Sexual Dysfunction in Women with Interstitial Cystitis/Bladder Pain Syndrome: A case-control study

Article link - <http://www.indianjurol.com/text.asp?2020/36/3/212/288620>

Publishing date:
1st July
2020

Reference:

This piece of information is adopted from IC Network website and is available at <https://www.ic-network.com/interstitial-cystitis-resources/intimacy-sex-ic/>. This information targets the patients of IC/ PS suffering from sexual dysfunction and may be used as handouts also if required.



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