

INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME AND SEXUALITY – AN OVERVIEW

IC/BPS is a chronic bladder disease causing pain, a frequent need to urinate day and night and often an urgent need to urinate due to overwhelming pain or unpleasant sensation.

The consequent lack of proper sleep, together with the impact of the disease on every aspect of the patient's life, forms a significant cause of stress, anxiety, exhaustion and depression.

IC/BPS has multiple ramifications, including on the sexual life of both male and female patients. Despite the fact that we are living in the 21st Century, in so-called sexually enlightened times, genito-urinary disorders are still taboo and stigmatised, while talking to other people – even to health professionals - about the negative aspects of your own intimate sexual experiences is difficult and embarrassing.

Sexual relationships play an important role in our lives and are of course the foundation of our very existence. Sexual intercourse is a normal part of intimate relationships with partners. IC/BPS, however, can have a disruptive and distressing impact on sexual relationships since penetrative sexual intercourse may be painful for males and females, both during sex and afterwards. For some women, intercourse may be totally impossible because the urethra, bladder, vagina and vulva are too painful and sensitive, while in the case of men ejaculation may cause them intense pain.

Anatomically, in women the bladder and vagina are in close proximity and this in itself can lead to pain or discomfort during penetrative intercourse. Furthermore, many female IC/BPS patients also suffer from vaginal pain, or may have a permanently painful, hypersensitive vaginal epithelium, due sometimes to the impact of recurrent candida infections (particularly patients with both IC/BPS and Sjogren's), or the vulva and entrance to the vagina and urethra may be inflamed, sore and painful to the touch. There may also be pelvic floor muscle dysfunction.

This means that in women there can be several different types of pain related to intercourse:

- superficial (that is on entry),
- pain in the vagina during thrusting or any internal contact,
- and deep pain due to pressure on either the painful bladder or other pelvic organs.

Many female patients may experience pain or burning sensation in the vagina, bladder and urethra after sexual intercourse, often for days or longer, causing heightened frequency and even full-blown flares.

Sexual pain affects all aspects of sexual response, for example desire, arousal, orgasm, satisfaction as well as actual intercourse. Once experienced in a negative way, there may be fear and anxiety of it happening again.

However, it should be emphasized that it is not only pain that is the issue here. There is also the urgency/frequency issue, since a need to rush to the bathroom when things are just

getting going is also a big turn-off and may make the patient anxious and nervous, as well as embarrassed by the fear of having to break off halfway due to the overwhelming sensation of needing to empty the bladder.

A few basic tips:

- Optimal pain treatment 15-20 minutes before sex can help the problem of painful sex in female patients. (However, it should be noted that use of painkillers such as NSAIDs may lead to erectile dysfunction in men!).
- a warm bath or shower is advisable to relax the pelvic muscles and to ensure thorough cleanliness by both partners to prevent infection;
- urination before and after sex is also important;
- use of non-irritating lubricants,
- engagement in foreplay to limit thrusting time,
- different positions to reduce pain and symptoms, and this will vary from patient to patient depending on the nature and location of the pain;
- thinking of creative ways of sex without vaginal penetration (this is known as “outercourse”) so as to maintain some level of sexual intimacy.
- Very important is to avoid sex during a flare-up.

If sexual intimacy is taken away, cracks may begin to appear in a relationship about which a patient may be very concerned and feel deeply guilty, inadequate and a failure, while the partner may also feel guilty about being the cause of such pain. There may consequently be decreased sexual interest, depression and a feeling of isolation. Communication between the partners is essential. It is important for patients to be able to discuss this problem with their partner and to try to find solutions together. But in practice this is often not the case.

Support helplines, which can be called anonymously, are intensively used by patients who are stressed and even suicidal about failing sexual relationships and above all perhaps the fear of losing their partner, since plenty of partners cannot cope with this kind of situation and simply walk away.

The sexual aspects of IC/BPS are frequently being missed since doctors often fail to raise the issue of sexual problems with their patients, while patients themselves may find it difficult or impossible to raise this intimate and embarrassing subject with their doctor, perhaps even more so if the physician is of the opposite sex. Furthermore, there are many cultures around the world where this is not only difficult but even taboo.

It is therefore important for the health professional to take the initiative in raising this issue, explicitly asking the patient if there are any sexual problems due to the IC/BPS symptoms, and if necessary referring the patient to a sexologist/sex therapist or relationship counsellor for help and advice.

Clinics treating these patients should therefore ideally have nurses and counsellors available who have been trained in sexual problems caused by conditions such as IC/BPS and other inflammatory bladder conditions.

Emotional support, empathy, understanding as well as practical support are needed from all professionals. Just being able to talk about it in a practical way with a professional may already take a great weight off the mind of the patient.

This is the first step towards overcoming embarrassment barriers on the path to finding solutions to the sex issue, while at the same time reducing the patient's emotional and psychological stress level and probably reducing depression too.

Resources for the patient

- Interstitial Cystitis Association (ICA <https://www.ichelp.org>)
Intimacy and IC/BPS <https://www.ichelp.org/living-with-ic/general-health-lifestyle-advice/intimacy-and-ic/>
- IC Network: <https://www.ic-network.com/interstitial-cystitis-resources/intimacy-sex-ic/>
- ICS News, 22, January 2010. Sexual Pain in Men and Women with IC/PBS and Chronic Pelvic Pain. Kristene Whitmore.
<https://www.ics.org/news/22>

Resources for the clinician

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