

INTERSTITIAL CYSTITIS INFORMATION CENTER
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**"LIVING WITH INTERSTITIAL
CYSTITIS"
NEARLY 120 THINGS THAT MIGHT WORK FOR YOU IN YOUR DAILY LIVES**

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Note that we're beginning to believe that the term Interstitial Cystitis covers chronic cystitis from many different origins (contrary to traditional medical beliefs). Many of us have not been diagnosed as having IC, yet the symptoms many of us have with "chronic cystitis" have similar elements. The following measures we have discovered within the NVA IC Support Group are helpful to most of us at least some of the time. Often they are useful on a regular basis.

ALWAYS CARRY THE MEDICATION YOU NEED WHEREVER YOU GO. This includes antibiotics, pain medication, antispasmodics, vitamin supplements--whatever you take on a daily or at least a frequent basis. Develop a routine that will make it happen.

Suggestions herein work for at least most IC patients, but there are always suggestions that do not work for other IC patients. Read and take for yourself what helps YOU most.

MENSTRUALLY-RELATED FLARE-UPS. (Men, some of these points apply to you too.)

1. Drink lots of fluids, mostly purified water if possible. Brita water filters work fine/inexpensive.
2. Lower salt intake.
3. Increase intensity of candida (yeast) control treatment: a) includes reducing sugar intake; b) increasing amount of Nystatin to 2 pills per dose, or double dose of Nystatin powder; c) if stomach can't handle this, ask medical practitioner for Diflucan (but beware this is more powerful than Nystatin and should only be taken for short periods of time). There are also natural supplements (not expensive) which can also be taken to prevent/control yeast development.
4. Pro-Gest Cream or Phytoestrogen Cream rubbed on forearm, thighs, abdomen provide a natural substitute for hormonal treatment.
5. Castor oil packs: a well-recognized treatment for many aches/pains: Pour castor oil on piece of clean flannel; put next to skin on suprapubic area; cover with Saran wrap; top with moisture proof heating pad or hot water bottle. Works for pelvic muscle spasms and bladder pain.
6. There are progesterone-blocking drugs such as Tamoxifen. We consider their use with caution. Side effects are frequent and may be worse than the bladder pain.
7. Change tampons and pads often so they won't be culture mediums for bacteria.
8. Better yet, don't use tampons because they put pressure on our urethras, causing pain and difficulty in urination.

9. If must use tampons, remove when urinating.
 10. Use washable cotton pads if the commercial pads found in healthfood stores or supermarkets irritate.
 11. Use heating pad on pubic area (20 minutes on, 20 minutes off). Alternatively, try putting cold packs on back side of pelvis in the L4-L5 area of spine (just above where the buttocks divide).
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Good when hard to urinate. Also useful to do both at same time when you can't sleep due to spasms.

HYGIENE

1. Empty your bladder at regular intervals. May practice bladder holding protocol to interrupt urgency patterns and stretch the bladder, if necessary. Should schedule at least 8 urinations per day.
2. Avoid constipation by eating plenty of vegetables and drinking water.
3. Drink only water; consider a minimum of 2 quarts a day. (Yes, do it!)
4. Avoid scented and deodorant soaps, vaginal deodorants, bubble baths. Use mild soap only and remember showers are best!
5. Don't swim in chlorinated pools; best not to go in any pools or hot tubs where bacteria easily collect.
6. Use only white toilet paper. May even want to buy unbleached toilet paper such as Seventh Generation Brand.
7. Take a rest during the day; get at least 8 hours' sleep at night.
8. When using toilet paper, ALWAYS wipe front to back to avoid contamination of urethra/bladder with bacteria.
9. Avoid douching. If absolutely necessary, use plain water or acidophilus solution or mild hydrogen peroxide solution. Do not do the last two solutions at the same time.
10. Avoid tight clothing which only adds to your discomfort.
11. Wear only cotton underpants as opposed to nylon, silk, etc.
12. Rinse underpants thoroughly after washing . One of our members, who admits she is obsessive, puts hers through 3 washing machine cycles with plain water after the cycle in which she uses soap. Another member just uses baking soda to launder them.
13. If you are really sensitive to soap, wear panty liners and/or wrap crotch of of underwear in non-bleached toilet paper.
14. Avoid nylon pantihose.
15. Wear knee highs, thigh high stockings or stockings with garter belt or pantihose with crotch cut out.
16. Shower daily; avoid tub baths.
17. Buy detachable hose for the sink beside your toilet. It fits on a coupling device you screw into your sink faucet. Sit on the toilet and use its spray to wash if you don't wish to take a complete shower. Use moderate water pressure so as not to drive contaminated water up into

your urethra. Rinse thoroughly. Can also keep an inexpensive spray bottle filled with purified water beside or on back of toilet and use in same manner. Also both are good to use after bowel movement (flush first). The bacteria then never have a chance to creep forward toward your urethra.

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SEXUAL ACTIVITY

1. Birth control pills, any medication with some progesterone content, may cause pain. Consider your options.
2. Diaphragms cause pressure on the urethra. Such pressure tends to create pain and infection.
3. Some don't recommend IUDs. May lead to pelvic inflammatory disease. They definitely stimulate uterine cramping which may stimulate bladder, bowel and vulvar/perineal pain.
4. Condoms are the preferred method for vaginal sex. They protect against infection as well as pregnancy. Female condoms are available; brand name is "Reality" (vaginal sheaths).
5. Spermicides may irritate the urethra.. Many IC patients cannot use them.
6. Both partners must be squeaky clean while making love. Shower, lathering and rinsing especially well from anus to urethra, including all the hairy areas. Clean under the nails while scrubbing hands. Wash again after intercourse.
7. Lubricants may be source of irritation. "Astroglide" is nonirritating and there are other such brands available. Avoid intercourse without sufficient lubrication.
8. Become proficient at non-vaginal methods of love-making; has positive effects on love-making beyond just protecting urethra! Doesn't include anal sex, which spreads bowel bacteria around.
9. Empty bladder before and after sex.
10. Drink water before and after intercourse.
11. Avoid major changes in level of sexual activity.
12. Avoid prolonged intercourse.
13. Avoid intercourse when having IC symptoms.
14. Avoid sexual activities that put pressure on the urethra; there are other positions which possibly may lessen the pressure than the traditional "Missionary" position
15. If not on antibiotics, take at least a single dose of one intended to kill enterococcus (such as Amoxicillin or Augmentin) after sex.
16. Take antispasmodic before sex (only if you're determined to have sex when you know you are vulnerable to spasms).
17. Try to reach orgasm quickly if you know it will hurt. It's ok to avoid. Vibrators may help or hurt. Clitoral stimulation may help some or set off urethral pain in others. Very individual as in all IC matters.

BODY POSITION

1. When sitting, sit upright to relieve pressure on muscle between anus/perineum and put weight on thighs. Also puts less pressure on piriformis muscle in buttock. Prevents spasms in vulva, perineum and anal/rectal region.
 2. When urinating, helpful to experiment with curving spine backwards or forwards to improve urine flow or to sit up straight so that nerve that goes from spine to bladder gives no pressure preventing emptying. Different for each person.
 3. When having difficulty urinating, you may need to get off the toilet and sit in a straight back chair and put ice pack on spine just above where buttocks divide for about 20 minutes. May also sit on ice pack. Reduces swelling and usually brings results when you get back on toilet!
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4. Ice pack in these areas helps anal/rectal and vulvar pain.
5. Separate thighs whether sitting, standing or lying down to decrease pain which may be associated with pressure on urethra, vulva, perineum and anus.
6. If you lie on your side, try putting small pillow between legs to prevent pressure on urethra and spine.

PSYCHOSOCIAL APPROACHES

1. Keep diary of what works and what doesn't for reference.
2. Take better care of YOURSELF!
3. Rethink roles. What are other options in fulfilling them?
4. Read all you can about IC. Educate yourself with the disease and its treatments.
5. Know that what you're experiencing is legitimate and real no matter what anyone else says.
6. Pay more attention to grooming, hair, clothes; makes one feel better about self.
7. Know it's ok to be angry about what is happening to you, to express your anger, then let it go.
8. Know it's ok to cry.
9. Know it's ok to pamper yourself.
10. Accept changes in your body, both bad and good. Adapt some, but don't accept changes that may not have to be permanent.
11. Accept the illness as an ongoing reality so you can use your energy to learn to manage it instead of fighting it.
12. Remind yourself others have worse problems/illnesses.
13. Joke about the disease whenever you can.
14. Be with people and do activities that make you laugh.
15. You have strengths and assets. Use them. Remind yourself that you have them---regularly.
16. Work with politically active groups helping IC patients.
17. Become more assertive with healthcare providers.
18. Take responsibility for your own health.
19. Seek specific treatments.
20. Avoid difficult situations/people.

21. Reduce workload where possible. Work "smarter."
22. When having upsetting thoughts, say the word "STOP."
23. Pretend you have a little key to the part of your brain that worries. Reach up and turn it off when you have worried enough.
24. Have a peaceful scene ready for your mind to replace unpleasant ones. Find a quiet place and focus on it.
25. Reduce expectations of perfection from yourself and others.
26. Slow down.
27. Plan ahead.
28. Consider options.
29. Learn to say "NO."
30. Be assertive about your needs.

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31. Don't allow the disease to take over your life.
32. Watch how other IC patients overcome their "worst case" scenarios and assure yourself that you can also handle yours.
33. Be willing to try new treatments/therapies.
34. Keep journal of feelings.
35. Seek counseling/psychotherapy to help you deal with your IC.
36. Set specific, progressive goals to handle situations.
37. Keep a detailed record of what you eat, do, and effects on IC symptoms.
38. Always have something else to try (e.g. alternative therapies, medications, supplements).
39. Get second opinions.
40. Resign yourself to knowing that improvements may take a lot of time and depend on a lot of outside resources, not just your own efforts.
41. Look for meaning in the experience. What you are learning now may apply to situations outside yourself that you never dreamed of.
42. Try to help others who have IC.

WHEN HAVING A BAD DAY/NIGHT

1. Say "ok, it's a bad day/night, so what?"
2. Take prescribed medications regularly and not just when you feel like it.
3. You have already made improvements. This is only a temporary glitch. Improvement never occurs in a straight line upwards.
4. Redefine pain as another sensation, for instance, pressure.
5. Enclose the pain in a box, mentally. Throw the box away and watch it sail off where you cannot see it anymore.
6. Focus on nonpainful sensations--the gentle feeling of breath going in and out of your nostrils.
7. Remember that bad symptoms don't last forever.
8. Read or watch TV to distract yourself from IC symptoms.
9. Distract yourself also with puzzles, math, craftwork.

10. Listen to music that soothes your soul; play music; sing
11. Use your hands in gardening, working with clay, painting.
12. Read a book of affirmations or positive self-talk.
13. Socialize when able; don't isolate yourself from others.
14. Call a hot line (good at night when everyone is asleep and you are not).
15. Keep busy.
16. Use heating pad and/or cold/ice packs over bladder, between legs, at base of spine. Alternate heat/cold if helpful to you.
18. Avoid movement, especially jolting/jogging kind. Alternatively, may pace.
19. Talk with someone; meditate.
20. Go to bed; lie flat.
21. Rub sore points on buttocks between spine and hip joints; Arnica or other such salve good.
22. Get general body massage.
23. Important to learn progressive relaxation of pelvic muscles.

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