

INTERSTITIAL CYSTITIS INFORMATION CENTER
"TIPS TO HELP YOU DO A LONG-TERM IC ANTIBIOTIC
PROGRAM"
BASED ON DR. PAUL FUGAZZOTTO'S ORIGINAL CRC
PROGRAM
(C) KAY BENTON

OUR EVERLASTING THANKS TO TRISH SCHULTE OF ARIZONA, WHO PIONEERED AND BACKED DR. FUGAZZOTTO'S BACTERIAL IC THEORY YEARS AGO AND ORIGINALLY WROTE THIS ARTICLE IN ORDER TO HELP OTHER IC PATIENTS GET BETTER. LEST WE FORGET, OUR THANKS TO DONNA SELLMAN (DECEASED) WHO ALSO CONTRIBUTED TO THIS WRITING.

The following will help you in your battle with IC until you get to a point where the infection starts to subside. It may take some several months before you see a gradual improvement; others will take longer or shorter periods of time.

Don't be a quitter!!!! This program requires a lot of fine tuning and effort.

When considering the following tips consult your healthcare provider before taking any medication. Go to a provider (it doesn't have to be a urologist) who has an open mind and whom you think may be ready to consider well-applied logic. Discuss the program and these tips which were prepared by women who have experienced the distress of IC and have tried the medications and practices herein.

Keep in mind, however, that healthcare providers are people who have had many experiences which have given them information also and that it may be impossible to shake them loose from long-standing traditions. In the time that you have (and you need to remember that most providers make up their minds about you within

a minute or so of your entering their office) you cannot expect to completely re-educate them or to be treated successfully by them. You can, however, always leave educational materials about IC with them so you have at least done something for the “cause.”

If the first provider you see exhibits a closed mind to the idea of treating you for the type of bacterial infection identified by a broth culture, give the opportunity to another. You do not have to be helped by a urologist; any compassionate practitioner who is willing to write prescriptions for you can be your partner in a return to good health. Perhaps your family, ob/gyn, orthopedic, infectious disease physician, internist, nurse practitioner or other may be willing to help you.

We are not medical authorities of any kind, nor do we claim to have medical knowledge other than from what we have read, heard or seen in the media, but we have gained experience as patients and can report what has worked for us. You must remember, however, that what works for one person may not work for another. Again, consult your chosen healthcare providers. Some people may have side effects to the different medications and some may not. Read all you can about side effects to all medications. You may ask the pharmacist for the drug insert for any prescriptions you are given. The drug insert will tell what the medication is supposed to do for you, what dosages are usually prescribed, and give any contraindications and/or side effects to that medication.

IT IS FELT THAT IN ORDER FOR A LONGTERM ANTIBIOTIC PROGRAM TO WORK YOU MUST AVOID ALL CATHETERIZATIONS OR DILITATIONS, HYDRAULIC BLADDER DISTENSIONS, LASER THERAPY OR ANY SURGERY WHILE GIVING THE ANTIBIOTIC THERAPY A CHANCE TO WORK. THIS THERAPY MAY TAKE A YEAR, POSSIBLY 18 MONTHS OR EVEN LONGER. AVOID ALL INVASIVE THERAPY SUCH AS DSMO, ELMIRON, BCG, CHLORPACTIN, SILVER NITRATE, ETC. THESE TREATMENTS COAT THE BLADDER AND MAY FURTHER EMBED ANY EXISTING BACTERIA.

The enterococcus (strept group D) is a pathogen that is normally harmless when when found in the intestines. However, bacteria can

easily travel from a woman's anus after a bowel movement to the vagina and bladder because of their close proximity to each other.

To prevent reinfection and to ensure total recovery, strict hygiene rules must be followed:

1. Voiding with intermittent stop-and-release practice is useful in not only strengthening the bladder muscles but for clearing the urethra of as much urine as possible. At any other time, practice Kegel exercises to strengthen the pelvic floor muscles or work with a physical therapist who specializes in pelvic floor rehab.
2. In public restrooms, don't touch any toilet seat that has not been protected from contamination by paper liners. Take a paper towel or tissue, wet it and at least wipe down any part of the toilet your bottom may come into contact with.
3. You may want to use your own Kleenex-type tissues in restrooms outside your home. You can also carry and use unscented bacterial wipes which you can store in zip-lock bags in your purse for final clean-up after a bowel movement. Teach your children how to use these wipes also—always wipe front to back. Drug stores also have convenient wipes in refillable containers. Keep a box in each of your bathrooms for easy cleanups.
4. Both partners should shower before sex every time. Women should empty their bladders both before and after having sex to help flush away any possible bacteria.
5. Women should be checked periodically by their gynecologists. A yearly PAP smear is essential.
6. Most of us can't afford a bidet, but it has been suggested that French women have fewer bladder infections probably because they all use a bidet. You can do the same thing by using a shampoo hose which you can connect to your bathroom sink or tub and spray your perineal area with warm water after each use of the toilet. Another tip is to rinse off the

area with warm water from a squeeze bottle after urinating to ease burning. It's certainly cheap and it just might help!

YEAST – FUNGAL INFECTIONS

Yeast can exist as a normal non-invasive contaminate or as candida albicans (fungus). In the latter vegetative state, it is a pathogen which means it can cause an infection by invading the body tissues. As a contaminate, it is in the resting state. It should be identified by appropriate laboratory culture to know the phase it is in. There is a blood test for candida but it is not very reliable. Some women think because they have never had a yeast infection, they never will, only to find down the road that they suddenly have a severe yeast (fungus) infection which has become systemic (throughout the entire body). Steps CAN be taken to prevent a yeast buildup and prevent discomfort by following the experience of other women. Further information can be obtained from the ICIC's article on "Yeast Control: RX and non RX."

First reduce carbohydrates and use NO sugar (or other artificial sweeteners because they are bladder irritants) in your diet.

If lab tests indicate a fungal phase is present, an internal yeast treatment may be necessary at once. But when going on antibiotics at any time, a prescription for yeast medication needs to be obtained at the same time because the antibiotic will suppress the good bacteria that inhibit the formation of a yeast infection. The oral anti-fungal medications will act as a preventive to fight the invasive candida albicans.

There are several drugs for yeast infections: some are oral, others are vaginal creams or suppositories. Nystatin powder or tablets are very effective and come in a 500,000 unit dosage of from two to six tablets or capsules a day. Nystatin powder needs to be refrigerated at all times but the tablets do not need refrigeration. Monistat, Gyne-Lotrimin are vaginal creams which may help initially get the yeast under control quickly. Some women use 1-2 doses of vaginal cream a week to keep their yeast under control.\

Diflucan is a stronger oral drug on the market but is expensive for the long-term course. It can be obtained for a 1-2 day course or for longer periods if needed by your particular situation. Diflucan is not for vaginal yeast but for systemic yeast throughout your body. Consult your healthcare provider regarding its use.

Non-RX with natural ingredients include anti-fungals such as HPD's ProSeed (non-systemic yeast) and CanPlex (for systemic yeast). Others have used the oral Nystatin powder dabbed in the folds of the vagina after a shower as well as taking a capsule and emptying half of it and inserting the rest into the vagina. The plain powder contains less chemicals if you are allergic to other medications. Some of us are more irritated with the creams; lotions may be another alternative in the vulva area.

RESTORING GOOD BACTERIA IN THE COLON

Antibiotics kill off many good bacteria as well as the bad in the intestines and this imbalance of gut flora can be restored with products generally called Acidophilus. They come under many names from Poly-Dophilus by HPD, Primo-Dophilus, to Aller-Dophilus. Some need to be kept refrigerated after opening while others do not. Poly-Dophilus contains "good for you" bacteria known as FOS which enhances the ability of the probiotic to help you with the yeast infection problem. PD and others are good brands free of dairy products, corn, soy, wheat, sugar, preservatives, etc., but you need to check the labels of each brand before you decide which to buy. If you don't have good results from one, try another. It has been found to be just as effective to take 5-6 capsules in the morning and forget further dosage as it is to try to remember to take the acidophilus one hour before or one hour after taking the antibiotic. NEVER, NEVER, take the two products (antibiotic and probiotic) together as they will cancel out the benefits of each other.

Poly-Dophilus can be obtained from Duane Benton, HPD Distributor at 434-315-0060 or dbenton@moonstar.com.

Acidophilus will also help diarrhea. For severe cases, rice water may be tried. Take two tablespoons of rice (uncooked) and put on one cup of water. Stir and drink the milky water left – add more water, do

not eat the uncooked rice. This is an old-fashioned remedy that has helped some. And because it adjusts the flora in your gut, it can also ease any constipation problems—you need to find what dosage works for you with this. You will learn how many capsules of probiotic you need by adjusting your dosage for a few days. Three to four is usually a good number, but if things are out of hand you may need to go to six – twelve caps a day.

ANTBIOTIC THERAPY

1. Antibiotics must be taken at regular intervals to maintain a constant level in the bladder – even through the night. Monitor and adjust dosage according to weight; experiment for tolerance. There are now two medical labs which will perform broth cultures for IC patients; neither need orders from a medical doctor. If you've been sending to Dr. Fugazzotto for cultures be prepared for "sticker shock" re prices for the current costs from these labs; info for both given in separate info article.
2. A pill splitter is a help. The baby blue-colored splitter for \$4-6 is still the best and can be found at almost any pharmacy. Try smaller doses of new medications to which you think you might be somewhat allergic. To divide a powdered capsule in half, pull apart the capsule dividing the powder. Put butter on both exposed ends and use one half, then put the other half in the refrigerator until needed. Peanut butter will also work to keep the powder inside the halved capsule.
3. If you are taking Augmentin and your pelvic pain becomes worse; you may want to use your pill splitter to divide the Augmentin dose into 4ths and mix it with Amoxicillin. Augmentin is clavulanic acid with Amoxicillin. The clavulanic acid may need to be reduced. Or there is also a chewable form of Augmentin usually given to children and it has one-half the clavulanic acid that the regular Augmentin has. REMEMBER: Everyone will require a different antibiotic adjustment according to their very own culture sensitivities. The same bacteria in two people may require different antibiotics and doses. This is very important to remember!
4. The drugs Septra and Bactrim (sulfamethoxazole and Trimethoprim) have produced adverse effects in most of us.

Sulfa-type drugs also produce allergic effects and they are not effective against gram-positive bacteria such as *Gaffkya* (*Micrococcus*) and *Enterococcus*. Augment, MacroDantin and even an older antibiotic Doxycycline are usually better and provide a more effective treatment. If using MacroDantin, the dosage that is suggested to work best is 100mg four to six times a day, not the usual 50 mg/doses. The lower doses are an ineffective dosage for *enterococcus*—the bacteria seem to thrive on this low dose. Again, whatever antibiotic you begin, ask for the product insert from the pharmacist and check for the side effects or contraindications.

OTHER IMPORTANT TIPS

The following suggestions are temporary measures to help with the pain until the antibiotics gradually take effect. Improvement in pain may be seen over a period of months with oral antibiotics. Again, consult your healthcare provider on all medications.

Pain management for chronic illness has changed a great deal. You don't have to live with pain anymore. Most everyone knows the pain of IC is not in your head, but in your bladder! Seek help from a pain management specialist. There also may be a pain support group you can attend in your area. Many hospitals have their own pain clinics.

You may also want to consult a physical therapist who specializes in pelvic floor muscle exercises. These exercises can help rehab those muscles which are often weakened in IC patients. The Kegel exercise is a very good one.

Elavil, a tricyclic antidepressant, helps with sleep but tends also to give unwanted weight gain to many. Its use seems also to lessen bladder symptoms, but how that works, no-one really knows. Also is reported to affect emotional response and problem-solving ability and is thought by some to be very addictive. Prozac, Zoloft, or Paxil are others that may be helpful to try. Antispasmodics are mentioned elsewhere.

Xanax, a tranquilizer, may be a temporary tool to help cope with

pain that gets unmanageable. Valium, an old-time tranquilizer, may also be taken to help with both pain and muscle relaxation. Lorazepam may also be helpful.

Tylenol 3 with Codeine is a narcotic pain medication. Torodal and Klonopin are other meds to help with chronic pain. All of these are Rx medications.

Ask to have blood tests run periodically to check kidney and liver function as well as other important physiologic functions. Have your sed rate and white counts checked. Most practitioners will agree that a sed rate higher than 20 indicates an infection somewhere in the body. To keep track of your records buy a loose-leaf notebook, divide it into sections and into it put all your medical test results, i.e., urine, blood, x-rays.

Insist that your sexual partner use a condom. It has become evident that the bacteria of IC can be transmitted from partner to partner. If you get treated for bacterial IC and do not use safe sex, you can possibly be reinfected. Also a male sexual partner should have his semen broth tested for pathogens for the same reason. Usually men are asymptomatic but if bacteria is found, it is prudent to have them treated with antibiotics for at least three months. Again, the broth culture should be repeated at the beginning of treatment, during treatment, and a month or so after treatment ends.

NO BATHS, SWIMMING POOLS, HOT TUBS, OR JACUZZIS.

Limit yourself to showers so that bacteria do not lodge in the recesses of your body. This is especially important if the theory that IC patients have "leaky guts" proves to be so. Bacteria can pass back and forth into the bladder if you have a leaky gut.

Vulvar vestibulitis and vulvar dynea are often characterized by burning, stinging, irritation, or rawness of the vaginal opening. The symptoms of either of these conditions may vary from mild to severe. Approximately 25-30% of IC patients experience some form of vulvar pain. Calcium citrate and potassium citrate are of help to some as is the use of a low oxalate diet. Polycitrate and bicitrate are Rx's that have been found to help some with the

acidic effect of foods. Prelief, however, is a similar product but can be purchased over-the-counter. Some women who become raw in the vulvar area stop wearing any panties. If you still wear them, make certain they are cotton only and are not tight. Also avoid tampons, slacks or other tight clothing. Pantyhose are not for IC patients either, as they tend to hold in moisture and certain bacteria love a moist warm environment. You can always cut out the pantyhose crotch. Some find relief is using ice packs during a state of flare. Baking soda douches may also temporarily help inflamed areas. Some have found relief from vaginal burning by pouring Epsom salts in the bathtub with enough water to cover the salts and your perineal area. Don't stir the salts. Sit on the salts for a short period of time (about ten minutes) as often as you wish. Talk with your gynecologist and get in touch with the national organizations for both of these problems.

Lebsin SL helps with anorectal and pelvic/abdominal spasms. Urispas or Urised may help with bladder spasms. Pyridium, actually an analgesic, does the same thing though it colors clothing orange – yuk!

HELP YOURSELF BY READING ALL THE MATERIAL YOU CAN ON IC. Other helpful reading material may include the Merck Manual, Tabor Medical Dictionary, and an annual nursing handbook . You can also find numerous drug reference books both hardback and softback.

Hank Liers' Health Products Distributors put out several suggested vitamin/mineral supplement schedules designed for IC patients to help heal their damaged bladders and their whole bodies. Info on these and other subjects is available from Ruth Kriz at rhkriz@aol.com.

IMPORTANT: AVOID COFFEE, ANYTHING WITH CAFFEINE, INCLUDING CHOCOLATE, ALCOHOL, AGED CHEESES, NUTRISWEET OR OTHER ARTIFICIAL SWEETENERS, SPICY, SALTY, ACID-TYPE FOODS, MSG, NITRATES, SULFITES, AND PRESERVATIVES. These are all bladder irritants and thus can produce pain in an inflamed bladder.

FURTHER NOTES

When preparing a specimen for culture be sure that you do not contaminate the urine with a Betadine wash (used when catheterizing) or alcohol wipe or any other kind of bladder instillation. These can lead to negative culture reports. For example, a small amount of Betadine can enter the urethra via a catheter, suppressing bacteria and result in a negative culture report.

Avoid strenuous exercise – no aerobics: try gentle yoga stretching; if back problems persist for you then see a massage therapist, acupuncturist or chiropractor regularly. Biofeedback and meditation may also prove helpful.

You can also become an IC advocate: write to your congressmen: tell them of your terrible illness, encourage them to fund further research on IC.

DON'T BECOME IMPATIENT – STAY WITH THE PROGRAM!!

REMEMBER AGAIN, THE ABOVE ARE ONLY SUGGESTIONS FOR YOU – CHECK WITH YOUR HEALTHCARE PROVIDER ON ALL COURSES OF TREATMENT.