INTERSTITIAL CYSTITIS
AGENGA

I. What is Interstitial Cystitis?
    a. The Urban Institute in Washington, D.C.
    b. Pregnancy and Interstitial Cystitis
II. Who Has Interstitial Cystitis?
III. Possible Causes of Interstitial Cystitis
    a. A history of urinary tract infections
    b. Bacteria, virus, or fungus
    c. Antibiotics
    d. Autoimmune disorder
    e. Deficiency in the bladder lining
    f. Toxic substances in the urine
    g. Abnormal numbers of mast cells
    h. Abnormal metabolism of tryptophane and serotonin
    i. Hormonal factors
    j. Pelvic surgery
IV. Preparing for your doctor's visit
V. Diagnosis
    a. Misdiagnosis
    b. The Key to Getting a Correct Diagnosis
    c. Diagnostic Tests
        1. A urine culture
        2. A urine cytology
        3. A kidney x-ray (intravenous pyelogram or IVP)
        4. A cystometrogram (CMG)
        5. A uroflow
        6. A residual urine test
        7. Electromyogram (EMG)

VI. The Classification of Interstitial Cystitis

- **a. Those with symptoms, but no unusual findings**
- **b. Those who have symptoms and abnormalities in bladder or urethral function**
- **c. Those who have symptoms and the bladder cracks, bleeds, or hemorrhages**
- **d. Those who have symptoms and the biopsy shows the increased presence of mast cells in the bladder wall.**

VII. Treatment

- **a. Endoscopic Therapy**
- **b. Laser Treatment**
- **c. Bladder Instillations**
- **d. Drugs**
  - **1. Sodium pentosanpolysulfate (Elmiron)**
  - **2. Amitriptyline (Elavil)**
  - **3. Non-steroidal anti-inflammatory agents**
  - **4. Alpha blockers**
  - **5. Oxybutynin chloride (Ditropan XL)**

VIII. Alternative remedies

- **a. TENS Unit (Transcutaneous electrical nerve stimulation)**
- **b. Bladder Retraining**
- **c. Acupuncture and Acupressure**

IX. Self-Help Strategies

- **a. Diet**
- **b. Vitamins and Minerals**
- **c. Stress Reduction**

X. Major Surgery

- **a. Augmentation Cystoplasty**
- **b. Urinary Diversions**
  - **a. Koch (Indiana Pouch) or Urinary Conduit**
  - **b. Cystectomy**

References:

1. Fall, M., Johansson, S.L., and Aldenforg, F.: "Chronic Interstitial Cystitis: A heterogenous syndrome," ***J. Urol.*****, 137:35, 1987**

2. Hunner, G.L.: "A rare type of bladder ulcer in women: Report of cases," ***Trans. South. Surg. Gynecol.*****, 27:247, 1914**

3. Held, P., Pauley, M., Hanno, P.M.,and Wein, A. J., Urban Institute Survey on Interstitial Cystitis, Workshop on Interstitial Cystitis, National Institutes of Health, Bethesda, MD., August 1987

4. McDonald, H.P., Upchurch, W.E., and Artime, M.: "Bladder dysfunction in children caused by interstitial cystitis," ***J. Urol.*****, 80:354, 1958**

5. Held, et al., op cit.

6. Ruggieri, M.R., Hanno, P.M., and Levin, r.M.: "Nitrofurantoin is not a surface active agent in the rabbit urinary bladder," ***Urol.*****, 29(5):534, 1987**

7. Jokinen, E.J., Alfthan, O.S., and Oravisti, K.J.: "Antitissue antibodies in interstitial cystitis," ***Clin. Exp. Immunol.*****, 11:333, 1972**

8. Parsons, C.L., Schmidt, J.D., and Pollen, J.J.: "Successful treatment of interstitial cystitis with sodium pentosanpoloysulfate," ***J. Urol.*****, 130:51, 1983**

9. Dixon, J. S., Holom-Bentzen, M., Gilpin, C. J., et al., „Electron microscopic investigation of the bladder urothelium and glycocalyx in patients with interstitial cystitis," ***J. Urol.*****, 135:621, 1986**

10. Messing, E.M., "Interstitial Cystitis and Related Syndromes," in Walsh, P.C., Gittes, R.F., Perlmutter, A.D., and Stamey, T.A., eds., ***Campbell's Urology*** **Philadelphia: W.B. Saunders, 1986, pp. 1070-1092**

11. Dixon, J.S., and Hald, T., "Morphological Studies of the Bladder Wall in Interstitial Cystitis, in George, N.J.R., and Gosling, J. A., eds., ***Sensory Disorders of the Bladder and Urethra*** **.Berlin: Springer-Verlag, 1986, pp. 63-70**

12. Hanno, P.M., Levin, R. M., Moson, F.C., Teushcer, D., Zhou, Z. Z., Ruggieri, M., Whitmore, K.E., and Wein, A.J., :Diagnosis of Interstital Cystitis,: ***J. Urol.*****, 143:287, 1990**

13. Hanno, P.M., Workshop on Interstitial Cystitis, National Institute of Kidney and Digestive Diseases, National Institutes of Health, Bethesda, MD, August 28-29, 1987

14. Fall, M., Workshop on Interstitial Cystitis, National Institute of Kidney and Digestive Disease, National Institute of Health, Bethesda, MD, August 28-29, 1987
15. Hanno, P.M., and Wein, A.J., " Interstitial cystitis, I & II," *Am. Urol. Ass. Update Series,* 6(9-10), 1987
16. Sant, G.R., "Interstitial cystitis: Pathophysiology, clinical evaluation, and treatment," *Urol. Annual*, 3 1989, p.171
17. Dunn, M., Ramsden, P.D., Roberts, J.B.M., et al., "Interstitial cystitis, treated by prolonged bladder distention," *Br. J. Urol.*, 49:641, 1977
18. Fall, M., "Conservative management of chronic interstitial cystitis: Transcutaneous electrical nerve stimulation and transurethral resection," *J. Urol.*, 133:774, 1985
19. Shanberg, A. M., Baghdassarian, R., and Tansey, L. A., "Treatment of interstitial cystitis with the neodymium-YAG laser," *J. Urol.*, 134:885, 1985
20. Sant, G. R., "Intravesical 50% dimethyl sulfoxide (RIMSO-50) in treatment of interstitial cystitis," *Urol. (Suppl.*) 29 (4):6, 1987
21. Ibid., p. 19
22. Messing, E. M., and Stamey, T. A., "Interstitial cystitis: Early diagnosis, pathology and treatment." *Urol.*, 12:381, 1978
23. Hanno, P. M., Buehler, J., and Wein, A. J., " Use of amitriptyline in the treatment of interstitial cystitis,: J. *Urol.*, 141:846, 1989
24. Wein, A. J., "Pharmacologic treatment of lower urinary tract dysfunction in the female patient,: *Urol. Clin. N. Am.*, 12(2), 1985
25. Fall, M.: "conservative management of chronic interstitial cystitis: Transcutaneous electrical nerve stimulation and transurethral resection,: *J. Urol.*, 133:774-778, 1985
26. Gillespie, L.: *You Don't Have to Live with Cystitis!* New York: Rawson Associates, 1986, p. 244
27. Catalona, W. J.: "Bladder Cancer," in J. Y. Gillenwater, et al., *Gillenwater's Adult and Pediatric Urology.* Chicago: Yearbook Medical Publishers, 1987, p. 1024
28. Mindell, E.: *Earl Mindell's New and Revised Vitamin Bible*, New York: Bantam Books, 1985, p. 80

WHAT IS INTERSTITIAL CYSTITIS?

Interstitial cystitis literally means cystitis, or inflammation, in the bladder wall. In this case, however, the inflammation does not appear to come from an invasion of bacteria. Its cause is unknown. Because the symptoms vary so much from person to person, and response to treatment is so unpredictable, doctors specializing in IC are beginning to think about it as a "symptom complex" with a number of possible causes.

Since it is difficult to say exactly what interstitial cystitis is, it is perhaps easier to describe the symptoms that you might experience and its signs-objective evidence of disease. (A sore throat is a *symptom*; the reddened mucous lining of the throat is a *sign*.)

In 1987, the Urban Institute, a social policy research organization in Washington, D.C., conducted a survey which provided the first in-depth look at the lives of people with interstitial cystitis.*[2]

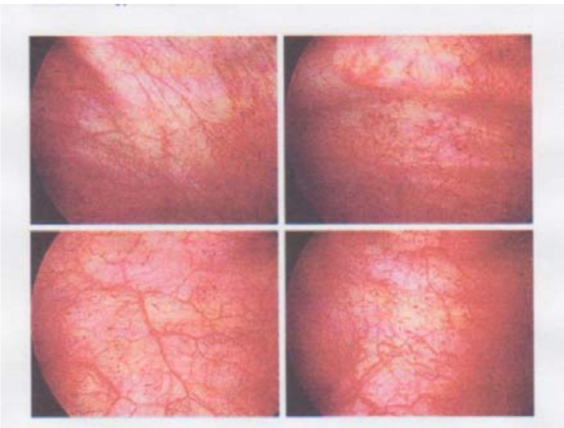
The respondents noted the following classic symptoms:

- **Waking at night two or more times to urinate (85%)**
- **Urgency of urination (84%)**
- **Frequency of urination-15-50 times in 24 hours (80%)**
- **Pain in the bladder, urethra, or vagina (78%)**
- **Pain relieved by voiding (57%)**
- **Painful intercourse (57%)**
- **Difficulty in emptying the bladder (51%)**
- **Difficulty in starting flow (47%)**

For many people, especially those with milder cases, the symptoms may wax and wane and unpredictable flare-ups can be difficult to bring under control. Some people with severe cases perceive pain as pressure, burning, "electric shocks," spasms, or stabbing pain that is present almost continually. "Some days may be better that others, but the pain is always there," says Constance, who has had IC symptoms for twenty-seven years but was only diagnosed in 1984. In addition, many of the women who answered our survey said that their symptoms usually or always flare up with ovulation and are usually worse from mid-cycle until one to three days after menstrual bleeding begins. Many people also reported that their symptoms are exacerbated by physical or emotional stress, acid foods, travel, and intercourse.

***This landmark survey was directed by Dr. Philip Held of the Urban Institute, the National Institutes of Health, the Interstitial Cystitis Association, Dr. Mark Pauly of the Wharton School, and Drs. Alan Wein and Philip Hanno of the University of Pennsylvania School of Medicine in conjunction with the Interstitial Cystitis Association. Randomized questionnaires were sent to more than 400 urologists and some of their patients, more than 900 female members of the ICA who had been diagnosed with IC, and more than 100 members of the general population.**

In 1915, Dr. G. L. Hunner published a paper on rare bladder ulcers in women who had urgent urination, extreme frequency, and sleep disruption due to the constant need to urinate Most of these women were post-menopausal and had been experiencing dire symptoms for an average of seventeen years. [3] Hunner identified large bleeding ulcers or sores in the bladders of many of them, and soon the presence of ulcers became the hallmark of the disease. With the rather primitive equipment available at the time. Hunner was probably seeing only the most prominent of many patients. Today, with instruments that provide clear visualization of the interior of the bladder, small hemorrhages can readily be seen. The ulcers that Hunner described bear his name today, but their frequency is quite rare, even in severe cases, and their presence or absence is no longer essential to a diagnosis of interstitial cystitis.



all - glomerulation of bladder consistent with IC

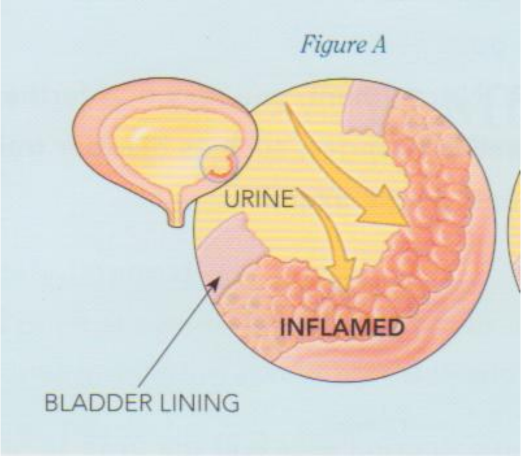


Figure A

While the signs of interstitial cystitis can't be seen with the naked eye, in many cases dramatic changes occur in the bladder, which can be seen through a cystoscope when the bladder has been overdistended (stretched to its full capacity) with water. Tiny pinpoint hemorrhages dot the bladder surface and blood may be seen in the urine. These *petechial* hemorrhages are now considered to be the hall mark of interstitial cystitis. In the worst cases, perhaps about 10 percent, the bladder lining becomes scarred from the ulcers and the bladder may shrink, becoming hard and fibrotic. Such bladders may hold only 1 or 2 ounces of urine at a time, as compared to 8 to 12 ounces for a normal bladder. "MY urethra just doesn't function very efficiently, says David, who has had interstitial cystitis for eight years. " Sometimes I just stand there for two or three minutes before anything happens, and a lot of times, it isn't worth the effort."

Although it is a singular disease in many respects, interstitial cystitis has some striking similarities with certain other diseases in which inflammatory processes predominate: lupus erythematosus, rheumatoid arthritis, asthma, irritable bowel syndrome, allergic rhinitis (nasal congestion due to allergies), and polyarteritis (inflammation of the smaller arteries). While many IC patients have no other major diseases, it is not uncommon for people with IC to have a constellation of these conditions. Liza is typical of this group. In addition to IC, she also suffers from inflammatory bowel disease, chronic low back pain, and allergic rhinitis.

Although there is no known correlation between interstitial cystitis and bladder cancer, many people with IC worry that they may be at higher risk for developing bladder cancer. At this time, there is absolutely no evidence that the chronic inflammation of interstitial cystitis stimulates the growth of bladder cancer.

Contrary to a widely held myth, *there does not appear to be any psychological cause for interstitial cystitis.* However, persistent symptoms can ultimately have severe psychological and emotional consequences. In cases of long duration, sleep deprivation and chronic pain may cause addiction to painkillers. The inability to work productively and to enjoy normal pleasures may cause feelings of personal failure, a poor self-image, and ultimately, depression—even thoughts of suicide. In general, interstitial cystitis is not a life-threatening condition and many people have learned to cope with it successfully. However, numerous IC patients report having suicidal thoughts three to four times more frequently than the general population, and there have been many reports of actual suicides.

One of the supreme ironies of this very peculiar disease is that, except for eyes that are puffy from lack of sleep or from tears of frustration, this enormous suffering is largely hidden, with none of the usual outward signs of illness such as pallor, a limp, palsy, or a noticeable fading of vitality. Interstitial cystitis has no outward, visible signs. In fact, many people have found that this is a significant disadvantage. "Friends don't really seem to understand that even though I might look okay, I get tired easily and can't do everything that they can do," reports Ida. Other people remarked that their friends thought them "undisciplined" or "neurotic" because they appeared to be in apparent good health.

Pregnancy and Interstitial Cystitis

In 1989, the Interstitial Cystitis Association did a survey on how women who have mild, moderate, and severe forms of the disease and became pregnant fared. The survey revealed that women who had mild symptoms often got worse and their symptoms remained worse for up to six months after delivery. Women with severe symptoms often seemed to improve, and remained that way for up to six months after delivery. Women with moderate symptoms appeared to remain much the same. As for pregnancy outcome, there was no significant difference in the number of Cesarean deliveries and the disease did not appear to have any impact on the general health of the infant.

WHO HAS INTERSTITIAL CYSTITIS?

Because under diagnosis of interstitial cystitis has been the norm for so long, it is difficult to say exactly how many people have the disease. The responses revealed some fascinating, if disturbing, data and dismissed, as well, some widely held myths about the disease.

According to the Urban Institute survey, there are somewhere between 20,000 and 90,000 *diagnosed* cases of interstitial cystitis in the United States. Doctors responding to the survey acknowledged having an average of five patients with some form of the painful bladder syndrome for every one who was diagnosed with IC, so perhaps five times as many people have the disease as have been reported—somewhere in the range of 100,000 to 450,000. Even if the lower figure is considered, IC is far more common than such well-known diseases as sickle cell anemia (40,000), cystic fibrosis (50,000), and hemophilia (20,000). Because of the tendency toward under-diagnosis, the Urban Institute data suggest that the number of people who have interstitial cystitis approaches the higher figure of 450,000.

Ninety percent of interstitial cystitis patients are women. Prior to this survey, IC was thought to be primarily a post-menopausal disease. This may have been because it took people so long to get diagnosed. However, the survey found that quite the opposite was true. The average age of the onset of symptoms in this study was forty, and 25 percent of the diagnosed respondents were under thirty years of age. Earlier medical literature tells us that a small number of teenagers and children have also been diagnosed with the condition.[4] The Urban Institute survey found few black women and even fewer black men with IC. But until more extensive research is done, we cannot make the assumption that the incidence of IC is necessarily lower in blacks or other minorities. The dramatically lower figures may be a reflection of minorities' lack of access to health care.

POSSIBLE CAUSES OF INTERSTITIAL CYSTITIS

Doctors who work closely with interstitial cystitis are baffled by the peculiarities of the disease and, to date, do not have any concrete information on its causes. But until we understand the potential causes, we cannot develop reliable, effective treatments. A number if intriguing theories regarding possible causes have been proposed, but so far there is little concrete evidence to support any of them:

- **A *history of urinary tract infections.* Childhood bladder problems are ten times more common in people with IC than in the general population, and adults were ten to twelve times as likely to have had one or more UTIs.[5]**
- ***Bacteria, virus, or fungus.* One early theory held that interstitial cystitis was caused by some type of infection, such as *Streptococcus*, but so far no evidence has been found to support this idea.**
- ***Antibiotics*. Since an overwhelming majority of IC patients have been treated with antibiotics for UTIs, it has been suggested that these drugs might somehow damage the bladder lining. One study has shown that nitrofurantoin, an antibiotic commonly used to treat UTIs, does not damage the rabbit bladder,[6] but it is not clear how this antibiotic interacts with the human bladder lining.**
- ***Autoimmune disorder*. The chronic inflammation in the bladder characteristic of IC resembles an autoimmune disorder in which antibodies (substances that form in the bloodstream in response to invasion from a foreign substance) act on the bladder wall in some way. To date, no bladder antibodies have been found.[7]**
- ***Deficiency in the bladder lining.* The bladder lining is coated with a thin layer of a sugar-based substance called *mucin* by some researchers and *glycosaminoglycans* (GAGs for short) by others. The filmy layer coats the bladder somewhat as Pepto-Bismol coats the stomach, preventing toxins or bacteria in the urine from gaining access to the delicate inner layers of the bladder wall. The positive response of many IC patients to Elmiron, a drug that acts as a synthetic GAG layer, ahs provided some support for the idea that the bladder lining may be defective in some way.[8] Yet no substantial difference in the GAG layer of people with IC and those with normal bladders has been found.[9]**
- ***Toxic substances in the urine.* Some doctors who work closely with IC have speculated that there may be toxic substances in the urine that might irritate or injure the bladder lining. The fact that severe IC symptoms disappear completely in most cases when the urine is diverted from the bladder to an interior "pouch" or to an outside collection bag suggests that the urine may contain some substance that sets off an inflammatory process. [10]**

- ***Abnormal numbers of mast cells.*** **A good bit of research interest has focused on mast cells, commonly found in connective tissues throughout the body, which release histamine and other substances when they break up or degranulate. Some studies have suggested that mast cells are found in higher concentrations in the bladders of about one half of all IC patients.[11] However, a recent study found elevated levels of mast cells in higher concentrations in non-IC patients who had other bladder disorders than in those who had been diagnosed with the disease.[12] Until further research is done, it is not clear what this means. It does suggest, however, that elevated levels of mast cells in the bladder wall can't be used as a definite sign or "marker" in the diagnosis of interstitial cystitis.**
- ***Abnormal metabolism of tryptophane and serotonin.*** **Some question has been raised about the role of serotonin and its precursor, tryptophane, in the disease process of interstitial cystitis. These potent chemicals, found in the brain and nervous system, affect sensory perception, sleep patterns, the transmission of nerve impulses, and the constriction of blood vessels—all areas in which people with IC have problems. Not much research has been done in the field, but there has been a lot of speculation about whether foods containing tryptophane increase IC symptoms.**
- ***Hormonal factors.*** **The fact that 90 percent of interstitial cystitis patients are women has led researchers to speculate about the possible role of hormones in the disorder; which hormones, and how they affect the bladder, is still a mystery.**
- ***Pelvic surgery.*** **The fact that about one third of IC patients had a hysterectomy, Cesarean delivery, or some other type of pelvic surgery prior to coming down with the disease has prompted some speculation about the role of surgery or perhaps anesthesia in the development of the disorder.**

This review of the possible causes of interstitial cystitis raises many questions but provides few answers. Clearly, a great deal of painstaking research will need to be done before we begin to get a more complete picture of the disease. There are a number of pilot studies now under way that should give us a bitter understanding of basic bladder function. Hopefully, this research will help uncover the cause of interstitial cystitis and lead to a cure.

PREPARING FOR YOUR DOCTOR VISIT

Because there is no specific test for interstitial cystitis, your symptoms and your medical history are very important in evaluating whether or not you have the condition. Here are some suggestions for things you might do beforehand to help make your visit more valuable:

- **Make a two- or three-day voiding diary.**
- **Make a written summary of your medical history, including diseases you have had, current medical conditions, hospitalizations, surgeries, and allergies to medicines or foods.**
- **Make a list of your symptoms and how long you have had the symptoms**
- **If you have pain that is relieved by emptying your bladder.**
- **What event, if any, precipitated your symptoms**
- **If you have a history of urinary tract infections**

- **If anyone else in your family has bladder problems**
- **If you have any allergies**
- **If you can identify things that worsen your symptoms**
- **List all prescription and over-the-counter drugs you are currently taking including birth control pills and any "recreational" drugs, and note any drugs you have taken and how long you took them.**
- **Write a brief summary of your recent sexual history, including the number of partners you have had, the types of activity you engage in. If applicable, include your contraceptive history.**

DIAGNOSIS

Until interstitial cystitis began getting some attention from prominent urologists around 1986 and 1987, when diagnostic guidelines were established, diagnosis of the disease was a hit-or-miss proposition even when the symptoms were very compelling. The Urban Institute survey found that people with IC symptoms saw an average of two to five doctors over a period of more than four years before obtaining a correct diagnosis. Indeed, it is not unusual for someone to see ten or more doctors before getting a correct diagnosis. In a letter to the Interstitial Cystitis Association, Helena described a typical series of misdiagnoses: "I have suffered from vague, painful urinary symptoms on and off for four years. I am twenty-seven and this 'reaction to stress,' 'psychosomatic problem,' 'reaction to sec,' or 'urethral syndrome' makes my life horrible when it strikes. I am losing my mind and do not know where to turn."

Rebecca's survey on interstitial cystitis revealed a wide variety of conditions with which people with interstitial cystitis have been misdiagnosed:

Psychological problems
  - **Need to find a lover or get married**
  - **Suffering from not having a baby**
  - **Nerves/depression/nervous breakdown**
  - **Being a complainer/wanting attention**
  - **Nee to get life in order**

Urethral problems
  - **"Urethral syndrome"**
  - **Small/underdeveloped urethra**
  - **Urethral stenosis/stricture of the urethra**
  - **Faulty location of urethra**
  - **Voiding problems**

Bladder problems
  - **Urinary tract infections**
  - **Trabecular (scarred) bladder**
  - **Calcium deposits in the bladder**
  - **Urinary retention**
  - **Spastic bladder**
  - **Fallen bladder**
  - **Trigonitis**

Gynecological problems

- **Endometriosis**
  - **Uterine polyps**
  - **Embedded ovary**
  - **Fibroids**
  - **Tumor on ovary**
  - **Tubal pregnancy**
  - **Pelvic floor myalgia**
  - **Adhesions from surgery**
  - **Yeast**
- *Miscellaneous*
  - **Appendicitis**
  - **Fatigue syndrome**
  - **Multiple sclerosis**
  - **Rectal infection**

This list of rater surprising diversity illustrates widespread confusion about interstitial cystitis on the part of doctors and enormous frustration on the part of patients, whose complaints have often not been taken seriously or who have been treated for numerous conditions that they did not have. Being aware of the many conditions that can be mistaken for interstitial cystitis should help you avoid misdiagnosis. If you have the classic symptoms of interstitial cystitis and are told that you have any of the problems listed above, you should insist that your doctor carefully justify the diagnosis. If he or she cannot do this to your satisfaction, then you might do well to get a second or even third opinion.

The Key to Getting a Correct Diagnosis

Drs. Alan Wein and Philip Hanno have noted that ***the most frequent reason for misdiagnosis has been the physician's failure to consider the possibility of interstitial cystitis in the first place.*** **As Dr. Hanno further observes, "Many physicians do not even believe the condition exists."[13] Because there are no specific tests that can definitively identify the disease, the diagnosis of IC is essentially one of exclusion; that is, after other possible conditions have been tested for and excluded, and you still have symptoms, then you probably have IC.**

Another prominent reason for frequent misdiagnosis is that the tiny hemorrhages that are considered the hallmark of interstitial cystitis are not usually visible on a cystoscope examination done in the doctor's office. They can only be seen when the bladder is overdistended (filled to its capacity with water) when you are under general anesthesia. Until recently, most doctors have been reluctant to subject young, apparently healthy people to the risks of general anesthesia when they did not think it was necessary. No doubt another reason for frequent misdiagnosis is a tendency on the part of many physicians not to take the symptoms of interstitial cystitis seriously, seeing many IC patients—most of who are women—as complainers, neurotics, or psychosomatics.

One of the consequences of misdiagnosis is mistreatment, which often compounds the problem and leaves you more miserable and confused than ever. With a better understanding of the interstitial cystitis syndrome, we can hope that misdiagnosis will

become the exception rather than the rule, and that the severe symptoms of the disease will be taken seriously and treated sympathetically by physicians.

Diagnostic Tests

If, on the basis of your medical history and voiding chart, your doctor suspects interstitial cystitis, he or she may order the following tests:

- **A *urine culture & sensitivity test* is a test which identifies the specific type of bacteria you have and which drugs will get rid of them. A few drops of your urine are placed on a dish with a special culture medium and incubated for about twenty-four hours. If infection is found, s sample of the same urine specimen is then placed on a blotter that is treated with different dinds of antibiotics and incubated for another twenty-four hours. If the bacteria are "sensitive," they will have bare spots on the blotter where these drugs are located. This test usually identifies a selection of several drugs that will kill a given bacteria. The results are normally available in about two days.**
- **A *urine cytology* test. This is a laboratory test in which urine is checked for cancer cells. The first urine of the day is preferred for this test, because it should contain a higher concentration of cells from the bladder wall since it has been in the bladder overnight.**
- **A kidney X-ray (*intravenous pyelogram* or IVP) or an ultrasound test to rule out abnormalities of the kidneys and ureters by injecting a dye into the veins which is concentrated by the kidneys and can be "seen" on the X-ray, outlining the kidneys, ureters, and bladder, and to look for other possible bladder abnormalities such as stones and tumors or pelvic masses.**

***Urodynamic* tests may also be done to assess basic bladder and urethral function:**

- ***A cystometrogram (CMG)* will show if the proper nerve signals are being sent and received by the bladder; it will also show how much urine your bladder will hold normally *(your functional bladder capacity)* and whether the bladder is emptying completely.**
- ***An uroflow test* measures the flow of urine to see how well you urinate over a period of time.**
- ***A residual urine test* will show the amount of urine left in the bladder after voiding.**
- **The function of the pelvic muscles will be assessed by an *electromyogram (EMG)*, which is a recording, on a graph or a screen, of the contraction of the muscles surrounding the urethra (the pelvic muscles). IN this test, electrical sensors are placed on the perineum, and the activity in the muscles is measured while the bladder is being filled with water, and then while it is emptying. This test determines whether the bladder and sphincter are working in sync, or if they are contracting and relaxing out of sync, causing bladder-sphincter dyssynergia (dis-coordination).**

The most important parts of the evaluation for interstitial cystitis are the over distention of the bladder and cystoscopic examination of the bladder's interior to look for hemorrhages. The bladder over distention is also one of the standard treatments. Because these procedures may be painful, they may be done under general anesthesia or intravenous sedation, and may or may not require an overnight hospital stay, depending on your doctor's reference. A biopsy of the bladder wall is often done at the time of the bladder distention, to rule out other obscure causes of symptoms. Like some doctors, Kistene often choose to begin conservative therapy, such as dietary changes and oral medications, before subjecting her patients to this procedure. Dr. Magnus Fall, who has done research on IC for many years at the University of Goteborg in Sweden, feels that biopsies are not always necessary in routine cases, noting that they are probably more appropriate for research purposes.[14]

THE CLASSIFICATION OF INTERSTITIAL CYSTITIS

In the not-so-distant past, many IC specialists referred to the more severe form of interstitial cystitis as "classic" disease. Others preferred to label mild to moderate disease as "early" and the more severe form as "late" IC. But these labels imply that "early" should at some point become "late," which is an issue that is far from settled. Most urologists who are familiar with IC believe that the condition of the bladder and symptoms do not deteriorate over time. In fact, the "early" form is often referred to as "non-ulcerative" IC. Drs. Hanno and Wein have suggested [15] classifying IC patients into four categories:

- **Those with symptoms, *but no unusual findings* from urodynamic studies, cystoscopic investigation, or biopsy;**
- **Those who have symptoms and *abnormalities in bladder or urethral function*, but the bladder appears normal when it is over distended and bladder capacity an biopsy are normal;**
- **Those who have symptoms and the *bladder cracks, bleeds, or hemorrhages* during distention and capacity is decreased;**
- **Those who have symptoms and *the biopsy shows the increased presence of mast cells in the bladder wall.***

These criteria take into account the tremendous range in symptoms and the disease process itself. They are not highly specific, but they offer patients and physicians a general way to assess the severity of the disease and can provide some guidance in choosing appropriate treatments. As this classification illustrates, there is not a direct correlation between a person's symptoms and the condition of the bladder.

TREATMENT

Since the cause of interstitial cystitis is unknown, treatments are primarily aimed at alleviating the symptoms. People with mild symptoms may choose not to have some of the more aggressive forms of therapy, because these treatments may be quite uncomfortable for several days afterward. But even when the symptoms are very severe, a conservative approach is recommended, moving methodically fro the least invasive and most likely to work, to more drastic surgical treatments designed to block pain or to divert the urine. Each of these treatments may work for a certain percentage of patients, at least for a while. Burt more often than not, the symptoms return. One of the most discouraging realities about interstitial cystitis is that some people have tried every type of treatment and are still in pain.

Because the chance of success with medically accepted treatments is limited, interstitial cystitis patients have been particularly inventive about improvising self-help regimens and seeking out alternative treatments. Often these have been used as adjuncts to medical treatments and in many cases, changes in diet, personal habits, or lifestyle have resulted in significant improvement.

If you are suffering from severe pain and frequency, you may be tempted to try everything at once, but this scatter-gun approach might be counterproductive. Since the results of various treatments are so unpredictable, Dr. Grannum Sant of Tufts University in Boston recommends undertaking only one type of therapy at a time, suggesting that if something works but you are trying two or three new treatments, you won’t know what is working and may have to start from scratch again.[16] This seems like sound advice, unless your symptoms are very severe, in which case you may want to try anything that might bring them under control.

Endoscopic Therapy

Endoscopic procedures allow your doctor to “look within” an organ or body cavity. In urology, the endoscopy is done with a cystoscope, which allows direct visualization of the interior of the bladder and urethra. The following treatments may be performed in conjunction with endoscopy.

Distention of the bladder, also called hydraulic distention, is used in both the diagnosis and treatment of interstitial cystitis. In treatment, the bladder is filled with water for varying amounts of time, from a few minutes to several hours. About 30 to 50 percent of the people who undergo this procedure experience a lessening of symptoms for up to six months or longer.[17] After the procedure there can be some temporary bleeding or burning during urination. Some people experience a decrease in urgency and frequency quickly, but others may have to wait two weeks or longer until the irritation caused by the procedure subsides.

Some urologists believe that ulcers in the bladder may be a specific source of pain and that their removal can be helpful. In trans-urethral resection (TUR) or cauterization, a cystoscope is inserted into the bladder and through it a probe with a hot tip is inserted. The tip is used to burn away the ulcerated tissue and seal off blood vessels. Swedish researchers have had success in reducing pain in 40 and 70 percent of the cases they have treated.[18]

Laser Treatment

Many people who have relatively severe cases of interstitial cystitis have pain accompanied by bleeding from ulcers or hemorrhages in the bladder wall. A few physicians have had some success I stopping bleeding and reducing areas of inflammation (and hence reducing pain) with the neodymium-YAG contact laser, which is commonly used to remove cancerous tumors in the bladder. This type of treatment has been used for people who have not had success from other treatments such as DMSO and other bladder instillations. In the only recent report on laser treatments, about two thirds of the study participants experienced relief or improvement of symptoms, although many of them had a recurrence of symptoms from six to eighteen months after treatment.[19]

The primary complications of laser treatments are the danger of bowel perforation due to "scatter" or burning through the bladder wall. These problems can be minimized by restricting the laser energy output. In laser treatments, as in surgery, the skill of the practitioner is all-important, so you should choose the doctor who does your treatments with great care. Be sure to ask how many people he or she has treated with this type of procedure, how many people have been helped, and if any serious complications have from laser treatments, Kristene has treated about fifty patients using the neodymium-YAG laser, which eliminates the danger of "scatter," with excellent results.

Bladder Instillations

The industrial solvent DMSO has been used on everything from arthritis to sports injuries and many claims have been made for miraculous cures. Surprisingly, interstitial cystitis is one of the conditions in which some effectiveness has been documented. In fact, treatment with RIMSO-50, manufactured by Research Industries Corporation, is the only FDA-approved use of this compound.

It is not known exactly how DMSO works in the bladder, but researchers have observed it has many properties that make it a logical choice for the management of IC. In addition to being a powerful anti-inflammatory agent, DMSO may relax the bladder muscle, and appears to have analgesic properties that can soothe irritated tissues. Further, DMSO easily penetrates membranes, and if it is mixed with other drugs, it enhances drug absorption.[20]

A DMSO treatment can be done in the doctor's office in 15 to 20 minutes. In this procedure, about 2 ounces (one quarter of a cup) of DMSO, or a "cocktail" with other drugs, is placed into the bladder through a small catheter. The liquid is then held in the bladder for about 15 to 20 minutes. Some people find it difficult to retain the solution for the necessary amount of time, and that it can sting the urethra when it is released. DMSO can occasionally also cause a "chemical cystitis" (severe burning in the bladder) for several days afterward. Some people who have had this reaction find that taking Pyridium, a bladder analgesic, the day before the treatment, and drinking lots of water or taking baking soda afterward can help "cool the burn" and shorten the time of discomfort.

Another minor but less socially acceptable side effect of DMSO is a garlic-like odor on the skin and breath, which occurs for about a day after the treatment. Some people find this a particularly disagreeable side effect, especially at work or on social occasions. But others, like Myra, seem to roll with the punches and refuse to let a case of industrial-strength bad breath ruin a major social occasion. ON the evening of her first DMSO treatment, Mrya and her husband were supposed to take their daughter and a new boyfriend who they had not met to the Four Seasons restaurant in New York, "When I was getting dressed for dinner, my husband noticed that I smelled like garlic," she says. "He thought it was so offensive that we should break the engagement." Frantically Myra called her doctor, who assured her that the odor was perfectly normal, and advised her to drink lots of water. "I felt fine and could not smell it on myself, so I took a shower and used a lot of mouth spray. During the dinner, whenever my husband could detect the odor, he would tap me on the shoulder-more mouth spray." Myra reports that the evening went very well, and says that afterward she realized it was her first victory over interstitial cystitis.

The normal regimen is one DMSO treatment every week for four to eight weeks and then periodically as needed if the result is good. If you have not had significant improvement after six to eight treatments, however, you and your doctor should probably pursue other forms of therapy. DMSO has been found to cause deformities in animal fetuses, so its use is not recommended during pregnancy.

Several studies have carefully investigated the effectiveness of DMSO for mild, moderate, and severe cases of interstitial cystitis. In milder cases, from 50 to 90 percent of the study participants experienced moderate to excellent improvement.[21] In the most severe cases, 50 to 70 percent of the patients had good to excellent results. Some people, unfortunately experience no relief at all. Because of its positive track record, and its lack of long-term side effects in most people, DMSO has become one of the standard treatments for IC.

Some doctors have begun enhancing DMSO with a combination of hydrocortisone (another anti-inflammatory agent), heparin (an anticoagulant and a major constituent of the bladder's GAG layer), and sodium bicarbonate. Kristene uses a variation of this formula, substituting an 0.5 solution of bupivacaine, a long-acting local anesthetic, for DMSO. This cocktail seems to eliminate some of the discomfort that is typically associated with bladder instillation. The regimen seems very promising, offering relief to more than half of the people who have tried it, and formal studies are pending. Because no controlled trials have been done, no data exists to support the contention that these formulas work better than plain DMSO.

Chlorpactin is another solution that has been employed in efforts to alleviate the symptoms of IC. Before administration, a bladder X-ray known as a voiding cystourethrogram (VCUG) needs to be done to make sure that the ureters will be able to prevent the solution from traveling up to the kidneys, where it could cause major damage. Because the instillation of chlorpactin is painful, some doctors have started instilling a less concentrated anesthesia and cutting down on side effects afterward.

The use of chlorpactin in the treatment of interstitial cystitis presents a puzzling contradiction. On the one hand, it is caustic to the delicate mucous membrane lining of the bladder. On the other hand, after the initial pain has subsided, some people have gotten long-term relief. In one study, one third of the patients treated with chlorpactin had a remission of their symptoms for longer than six months and 70 percent experienced some improvement.[22]

Silver nitrate is another solution that has been instilled into the bladder to relieve the symptoms of interstitial cystitis. Older studies suggested greater than 50 percent of IC patients experienced relief of symptoms with silver nitrate, but its use is currently not very widespread and there is no recent data on its effectiveness.

Drugs

Given the complex and sometimes overwhelming manifestations of interstitial cystitis, the IC sufferer's pharmacopeia is understandably imaginative and extensive. One drug will seem to work fairly well for a substantial number of the people who try it, while giving others no help at all. Few studies have been done on most of the medications prescribed for IC; therefore, each drug tried is something of an experiment. But given the desperate situation of many IC patients, the experiment is often worth it. The following drugs are the ones that have been most frequently employed in the treatment of IC.

Sodium pentosanpolysulfate (Elmiron) is a synthetic sugarlike substance that appears to aid in restoring the protective lining of the bladder. In studies at seven sites being done to satisfy FDA requirements for approval, more than 40 percent of the patients had a reduction in pain, nearly 40 percent had a decrease in urgency, and 65 percent experienced a significant decrease in urinary frequency. Elmiron seems to be most effective in decreasing frequency. So far the chief side effect of Elmiron appears to be diarrhea in a small percentage of people, and a few people have also experienced bleeding disorders and hair loss.

You do not have to be in a study to get Elmiron. Your doctor can obtain it on a "compassionate use" basis, by contacting the manufacturer, Medical Marketing Specialists of Boonton, New Jersey. Elmiron is currently in the final phase of clinical trials and should be approved for general use by the Food and Drug Administration sometime between the end of 1990 and 1992.

Amitriptyline (Elavil) belongs to the class of drugs known as *tricyclic antidepressants* which have long been used to treat anxiety and depression. Because it blocks central nervous system activity and has a sedative effect, Elavil has also been successfully used in treating pain syndromes. The use of this drug for interstitial cystitis was discovered quite by accident when one of Dr. Hanno's patients began taking it for depression and experienced a dramatic improvement in her IC symptoms. Elavil is the least invasive of the treatments for IC and it seems to work well for many people in whom pain and/or nocturia are the most bothersome symptoms. In one study, 40 percent of the patients had a total remission for an average of eight months. [23]

In normal tissue, histamines are released from the breakdown of mast cells, causing an inflammatory response—pain, puffiness, and ultimately fibrosis, the formation of scar tissue in the bladder wall. Both prescription and over-the-counter *antihistamines* such as Benadryl have been used to counteract the effects of histamines.

***Non-steriodal anti-inflammatory* agents are another logical class of drugs used in the management of interstitial cystitis. These range all the way from over-the-counter medications like aspirin and ibuprofen (Advil, Motrin or Nuprin) to prescription anti-inflammatories such as naproxen (Naprosyn, Ananprox) and piroxicam (Feldene).**

***Alpha blockers* have been employed on a limited basis in the treatment of IC as well as urethral syndrome. These drugs interfere with nerve impulses to the smooth muscles of the bladder neck and urethra, blocking pain and relaxing the urethra. In the past, phenoxybenzamine (Dibenzyline) was widely used and is still prescribed today, but it has been found to cause cancer in laboratory animals, so its long-term use is not recommended. If your doctor prescribes Dibenzyline, ask him or her about possible alternatives. Prazosin hydrochloride (Minipress) is a newer alpha-blocking drug that can be used in place of Dibenzyline.[24] Some people find these drugs difficult to take because they relax *all* smooth muscles, including the blood vessels, and may make you feel at first as if "you stand up, your blood doesn't."**

Painkillers, muscle relaxants, and sleep medications are mainstays for many IC patients. For people with very severe symptoms, these preparations may offer the only respite available from un-remitting bladder pain. And for people who have trouble sleeping because of pain and severe frequency, sedatives may provide the only possibility of a few hours sloop. But the disadvantages of chronic use of the drugs in this category can be significant. Many people don't like the "drug hangover" that often occurs with narcotics and find it difficult to function normally if they take enough to kill the pain. In addition, the danger of addiction is significant. You might try going off a drug periodically and substituting another type of drug, or try alternative pain remedies such as acupuncture and acupressure, transcutaneous electrical nerve stimulation (TENS), or investigate the treatments provided by a pain clinic.

TENS Unit

Many people with interstitial cystitis experience chronic pain in the bladder, urethra, clitoris, vagina, or even rectum. Drugs may mask the pain or block nerve receptors that transmit pain impulses, decrease inflammation, or reduce pelvic congestion, but they may also mask your ability to function normally and may made you fell as if you've been out drinking all night. *Transcutaneous electrical nerve stimulation* (TENS) is one non-drug method of pain control that has long been used to reduce the pain of severe back injuries. It has also been successfully used in the treatment of interstitial cystitis in Scandinavia. This small batter-powered device provides a low level of electrical current which is transmitted by one-inch-square electrodes that are taped to the skin above the bladder and/or lower back. The unit itself is no larger than a phone beeper and can be worn on a belt or tucked into a pocket.

Some reduction in pain sensations should be felt within a few weeks, but you may not get the maximum benefit for at least a month or more. Therefore, use of TENS needs to be looked at as a long-term treatment. Scandinavian studies have suggested that people with severe symptoms seem to benefit the most from TENS therapy and have found that about 20 percent of these people could be classified as "cured."[25]

Dr. Naomi McCormick, a psychologist who has severe IC symptoms, used a TENS unit for more than a year. "I had poor results from most of the conventional treatments for IC and had side effects from pain medications, so TENS seemed a reasonable thing for me to try. I found that it was most effective with two electrodes taped over my abdomen or two over my lower back." The device causes a tickling sensation, and the intensity of the impulses can be adjusted for your own needs. McCormick points out that the electrical impulses of the TENS unit do not interfere with the transmission of pain impulse; rather, they distract you from it.

There is no danger to using the TENS device, but it is recommended that it only be used for about two hours at a time, especially if skin irritation develops. McCormick points out that you may need to be careful not to fall asleep with the unit on. "You can get skin irritation or even minor burns if you are not careful," she says. In these instances, she recommends the use of aloe vera gel to help heal irritated spots.

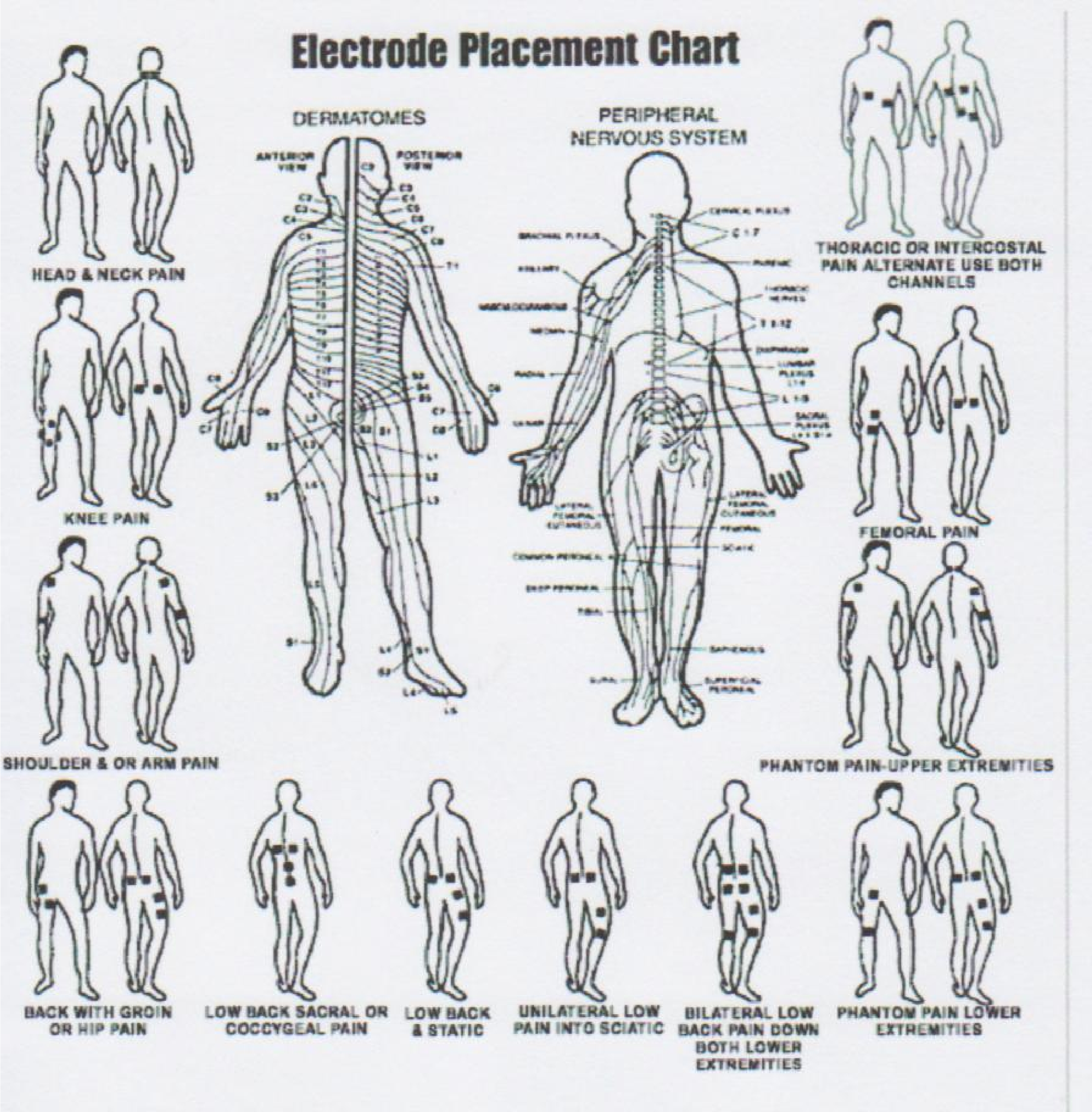
Using the Physiostim device, Kristene has found that pain is markedly decreased in about one half of the patients she treated by applying electrical stimulation directly to the vagina. The Physiostim is a device that combines biofeedback with electrical stimulation. To date, well over 10,000 women have used the Physiostim in Europe, and it has been reported that 75 percent of those who tried it experienced improvement or a cure. The Physiostim, manufactured by R.L. Medical, has a tampon-like vaginal probe for women and anal probe for men that delivers pulsating low-grade electrical current to the pelvic muscles. In the ongoing studies, each treatment consists of about 10 minutes of biofeedback monitoring of pelvic muscle exercises and up to 20 minutes of electrical stimulation. The strength of your muscle contractions is recorded by a computer and displayed on a screen. The computer compares the strength of your contractions with the intensity of the desired contractions selected with the aid of a computerized program. As a part of the program, you are required to do 5 minutes of pelvic exercises twice daily at home during and after the treatment period that consists of two treatments a week for 4 weeks, followed by one treatment a week for 2 to 44 weeks

These exercises and devices have an intriguing potential in the treatment of incontinence. For people who are good candidates for this type of treatment, they offer the possibility of a complete cure or significant improvement without any unwanted physical effects. And if you fail, you won't have lost anything but a little bit of time and the cost of the program.


TENS-1000
Pulse Width (µs)
Frequency (Hz)
GP
GREENCELL
EXTRA HEAVY DUTY


Tensunits.com

Electrode Placement Chart



Studies on the treatments described above typically find that about half of the people who try a given treatment respond positively, at least for a while. But the hard fact about interstitial cystitis is that there is no treatment that will eradicate symptoms for everyone. Even though many people experience some relief from medical treatment, they often find it necessary to supplement these treatments with alternative forms of therapy.

ALTERNATIVE REMEDIES

Bladder Retraining

Erin had a urinary tract infection after the birth of her second child. Antibiotics killed the bacteria, but a burning sensation remained. Eventually, the pain went away, and she was symptom-free for two years. Then, in 1985, her symptoms returned and she was diagnosed with interstitial cystitis. "On the good days, I go every hour," she says, "abut on my worst days; I have to go all the time." Erin had DMSO treatments but didn't get any relief, then took Elmiron for none months with no improvement in her symptoms. Finally, in desperation, she started a bladder-training program. "When I started the program, I went to the bathroom every half hour and often it wasn't worth the trip—nothing would come out, "she says. After three months of the bladder-training program, Erin increased the interval between trips to the bathroom to four hours. "It's still difficult on bad days, "she says, "but it's certainly better than before."

Bladder training, also referred to as bladder *retraining*, has been successfully used to help people with incontinence increase their bladder capacity by gradually increasing the amount of time between urination. Like any other muscle, the bladder muscle responds to repeated stretching by becoming larger and stronger. Nerve impulses to and from the bladder also respond to being "worked out" by firing less erratically. This technique has been adapted to use by anyone who suffers urgency and frequency, and has been especially effective with interstitial cystitis patients.

There are presently a small number of bladder-retraining programs in the United States, including one run by Susan Blaivas, a psychologist who practices in suburban New York City, and another by Paul Koprowsky, s asocial worker who works with Dr. Lowell Parsons in San Diego. " The goal of this program is to put people back in charge of their bladders," Blaivas says.

Blaivas runs a highly structured program that lasts for fourteen weeks. "At the end of that time, people should be voiding in response to a full bladder, rather than to ill-defined sensations," she says. Patients who enter the program fill out a detailed voiding diary, noting everything they drink, how much they urinate, and a number of more subjective fact ors, such as how much urine they *think* is going to come out. "This is an excellent consciousness-raising technique." Blaivas says.

The program may sound very easy, but for someone with interstitial cystitis who has intense urgency it can be very difficult. "If I was having a bad day, I did nothing but watch the clock," Erin says. "There were some days I thought I wouldn't make it." If the patient has a partner, Paul Koprowsky often has the partner come in so that he or she can get a clear understanding of the concepts of the program. "That kind of support is very

essential," He says. Koprowski also warns that after you have successfully completed the program, it is easy to fall back into your old habits if you are not careful.

Both of these programs use 15-minute increases each week and establish an appropriate amount of fluid to be consumed. Usually symptoms of frequency and urgency begin to decrease about the fifth or sixth week, and by the end of the program, many people can reasonably go 3-4 hours between voids.

Koprowsky has also treated quite a number of people who have "normal" bladders. Many people with bladders that show no signs of disease suffer from urinary urgency and/or frequency, and complain that they cannot go on long car trips or to unfamiliar places because of "tiny bladders." People who work at home, where they have constant access to a toilet, or teachers and therapists, whose work day is chopped up into many short segments, often establish a pattern of frequent urination, in which their functional bladder capacity decreases significantly (although the true capacity remains the same). In treating interstitial cystitis, Kristene has found that once the pain is under control, bladder retraining has been very effective in decreasing frequency.

Since there are so few programs available at this time, if you want to try bladder retraining, you will either have to do it by yourself, which many people can do effectively, or convince a therapist or other health-care professional to support you through a program.

Acupuncture and Acupressure

Acupuncture has been used in China for over a thousand years and was introduced in Europe in the seventeenth century. Today, the scientific basis for acupuncture's use in anesthesia, pain control, and healing has been widely validated, and the concept is being increasingly utilized in treating a variety or conditions. Many acupuncturists supplement needle stimulation with a variety of Chinese herbs that are known to have a beneficial effect on pain and inflammation. Acupressure is a technique similar to acupuncture. It utilizes the same points on the body, and s steady pressure, from light to very strong, is applied with the thumb and fingers.

In acupuncture treatments, very thin needles are inserted into the muscles at specific points located along meridians, or nerve pathways , and are turned manually, or may have a mild electrical current applied to them. When used in pain control, needles are inserted at specific acupuncture points which stimulate the release of certain chemicals, especially endorphins (the highly touted substance that produces the "jogger's high"), monoamine (a deficiency is thought to be involved in the manic depressive syndrome), and serotonin, a chemical involved in sleep and sensory perception. Each of these chemicals, or neurotransmitters, can interfere with the transmission of pain impulses.

In terms of bladder disorders, acupuncture probably has the most specific application to interstitial cystitis, where pain is a prominent component. This technique is known to be effective in reducing inflammation and in calming muscle spasms, and in treating subsidiary conditions such as allergies and immune deficiency (which may contribute to the IC syndrome). In response to Rebecca's survey, many people with interstitial cystitis said that they had tried acupuncture, and success was quite varied.

Quite a few people, like Lucinda, found that nothing, including acupuncture, was of much help in relieving the pain.

Acupuncture is frequently practiced by chiropractors, naturopaths, and osteopaths, by some MDs, and by a variety of other practitioners. If you decide to get acupuncture treatments, you might want to find a practitioner who has had some success in treating IC or other types of bladder pain.

In addition to undertaking bladder retraining, Erin has been having acupuncture treatments for IC for about ten months and is finally beginning to get some response. "Now I have good days far more often than I did when I was on medication," she says. "I used to have almost no good days, and now I have almost no really bad days and quite a number of good days. I feel I have made substantial progress--since I stopped taking any medication." For about eight months, Erin had treatments twice a week and has now cut down to once a week since she went back to work full-time. "Each treatment lasts about an hour and a half, and I usually have between 40 and 50 needles placed at different points on my body." Erin says that the needles don't hurt but may create sensations similar to small electric shocks. "Sometimes it feels like waves traveling though my body. Not really unpleasant." She reports that during the first weeks of treatment she felt "really drained" and experienced tingling sensations where the needle points had been, but both of these reactions subsided quickly. Erin's acupuncturist also prescribes certain Chinese herbs recommended for the kidneys. He says that her case is the most difficult he has treated, but he's very pleased with her progress.

SELF-HELP STRATEGIES

Because of the constant need for relief and the lack of satisfactory treatments for interstitial cystitis, a significant body of self-help information has evolved. *Every* IC patient has her or his trusted remedies and many have shared them in support groups. Some of these strategies, such as diet and stress reduction, are aimed at eliminating factors that may cause flare-ups of symptoms, while others are intended to minimize urgency and frequency and intensity, or to take the edge off of daily pain. Here is a survey of the elf-help strategies that many people have found helpful.

Diet

Many people who have interstitial cystitis say that diet is the single most important influence on their symptoms. Others don't see any apparent connections and practice no restrictions at all. Conventional wisdom tells us that you shouldn't eat things that make your symptoms flare up. Some people have found that a low-acid diet is very helpful. Dr. Larrian Gillespie recommends an acid-free diet in her book *You Don't Have Live with Cystitis!* for interstitial cystitis patients.[26] Although it is frequently referred to as "the Gillespie diet," Gillespie did not invent the low-acid diet. Such a regimen has been used for many years for a variety of conditions

More than one third of the people who answered Rebecca's survey said that acidic foods definitely make their symptoms worse, usually *much* worse, and some maintained that certain foods were "guaranteed to put me to bed." Foods that seemed to other people the least were carbohydrates such as rice, pasta, and potatoes, and chicken and meat.

Of all the dietary no-no's, alcohol headed the list, with caffeinated beverages (coffee, tea, caffeinated sodas), chocolate, citrus juices, and tomatoes following close behind. People mentioned a variety of fruits that tend to escalate symptoms, especially bananas, strawberries, and pineapple. Quite a number said that spicy foods were also likely to cause symptoms to flare up. Although people tended not to be specific about which spicy foods bothered them, certain ethnic foods, especially Thai, Indian, and Mexican, contain pungent spices notoriously high in substances that induce the body to release histamines—a prominent factor in the interstitial cystitis disease process. A significant number of people said that they have also given up wheat and milk products. Vinegar and soy sauce seem to bother many people, raising the question of whether is the acidity or fermentation (or perhaps both) that serve as bladder irritants. Some people said that fish or meat bothered them, while others found these items to be dependably non-irritating.

Some question has been raised about the role of the brain chemical serotonin, and its precursor trytophane, in interstitial cystitis. Tryptophane is present in a wide variety of foods, and is found in many of the foods that seem to exacerbate IC symptoms.

Rather than being recommended by a doctor, the diets of IC patients are frequently self-imposed, and some of them are extremely stringent. "I would eat dog food for the rest of my life if I thought my symptoms would go away," says Nina. And Clarissa observes, "You should like a fruitcake when you talk about your diet, but I feel that it's essential in controlling my symptoms."

If you think that food allergies strongly affect your IC symptoms, one way to pinpoint what you are allergic to is go on a strict "elimination diet," cutting out all but a core group of foods that don't bother you. Or you can look for a doctor or nutritionist who specializes in treating allergies. Arlene and Karen, who both have severe IC, found a doctor who specializes in treating food and environmental allergies. "At first we had to eliminate all but about ten or fifteen foods," Arlene reports. "Then it took six grueling months to get a clear picture of which foods were the baddies. We kept making mistakes and learning, but it was worth it." Arlene says that is was helpful to do the diet with another person. "It was so much better than doing it alone," she says. "We could support each other and share our successes and failures." Doing the experiment together was also instructive. "We were sensitive to entirely different things, and clearly saw that these sensitivities are very individual."

The existence of systemic yeast or a "yeast syndrome" is extremely controversial, and not widely accepted in the scientific community, but some people with interstitial cystitis have reported improvement with the yeast-free diet that is so popular today. The theory is that yeast or other molds can inhabit many systems of the body and that overgrowth can stimulate the development of allergies and ultimately suppress immune function. What effect this would have on the bladder is unclear. Nevertheless, a diet that eliminates yeasts, cheese, mold, alcohol, and other fermented products such as vinegar, soy sauce, and tofu provides a good basic elimination diet, leaving rice, potatoes, pasta, vegetables, meat, and chicken, the very things that our survey respondents say bother them the least.

The yeast-free diet is extremely stringent, and like Arlene and Karen, you may be on it for many months. The diet can be very difficult to maintain, especially for people who have significant attachments to food. It can also be difficult for people who cook for several others, as well as for those who eat out frequently or travel a great deal. *But it can*

be done, **and some people have had excellent results in reducing the symptoms of interstitial cystitis by eliminating or reducing their intake of foods containing yeast and mold. As an alternative to a strict elimination diet, some people have had excellent results with a rotation diet; that is, only eating troublesome foods every four or five days.**

Vitamins and Minerals

To date, no research has been done on the positive or negative effects of vitamins on interstitial cystitis. Indeed, the role of vitamins on normal bladder function remains to be determined. One minor exception has been in the area of bladder cancer, where vitamins A, B6, and C have been found to have a possible protective role in healing and preventions.[27]

Many people who responded to Rebecca's survey said that they take vitamins, and a few felt that they were essential to their dietary regimens, but most said that they did not seem to have any discernable effect on IC symptoms. However, if your diet is severely restricted, taking selected vitamin supplements might be very sensible. Regrettable, we can't offer you any specific information on vitamin therapy for interstitial cystitis; no one can. In order to help you evaluate which vitamins could *potentially* be helpful and which ones could be harmful, we will review what is known about certain vitamins and amino acids and their *theoretical* relationship to the metabolic processes that are known to be involved in IC.

Vitamin A **helps maintain healthy mucous membranes.**

Vitamin B Complex **influences, among many other things, the transmission of nerve impulses and carbohydrate metabolism. With the specific exception of B6, the B vitamins aid in the production of serotonin and its precursor, tryptophane, which some people believe may intensify IC symptoms. On the other hand, B6 is thought to help prevent the breakdown of tryptophane into serotonin. In addition, baking soda and oral contraceptives may destroy B6, so if you take either of these regularly,, you might want to consider taking a B6 supplement.**

Vitamin C, or ascorbic acid, **is not manufactured by the body, and must be obtained through food or vitamin supplements. Ascorbic acid may irritate the bladder, so IC patients should only take it buffered with calcium carbonate. A great deal of attention has been focused on the role of vitamin C in the synthesis and maintenance of collagen, a primary component of fibrous connective tissues. Vitamin C is also said to temper allergic responses by functioning as a natural antihistamine. Also it promotes the absorption of other vitamins, especially A and E.**

Calcium **is one of our most important dietary substances. In addition to promoting strong bones and teeth, it facilitates nerve transmission and muscle activity. Calcium is thought also to have a calming effect and to aid sound sleep. Both Vitamin D and magnesium, certain hormones, and especially estrogen are necessary for calcium absorption.**[28] **You can boost your daily calcium intake by eating antacid tablets, which are primarily calcium carbonate. Too much calcium, however, can cause urinary stones.**

Vitamin E, a natural vasodilator (helps blood vessels to open up), could be helpful in reducing the pelvic congestion that is common with interstitial cystitis. This vitamin is found in leafy green vegetables, broccoli, eggs, whole wheat, and many other foods.

Maintaining Alkaline Urine

The normal pH of urine, that is its acidity or alkalinity, is about 5 on a scale of 1 to 14:

1-----------5-------6---7---------------------14
Acid normal neutral alkaline

In her book *You Don't Have to Live with Cystitis!*. Dr. Larrian Gillespie reported that the urine of people with interstitial cystitis is typically alkaline (pH greater than 7) and that many of her patients found that acid foods cause symptoms to flare up. Other urologists, however, have found that the urinary pH of IC patients is extremely variable, ranging anywhere from slightly acid (pH 5 or 6) to slightly alkaline (8).

In response to Gillespie's report, many people with IC went on low-acid diets, while others have been restricting their diets for years because much of what they eat seems to have a negative effect on their bladders. But what does a "low-acid diet" really mean? Many people are confused.

Foods in their natural state are either acidic, neutral, or alkaline. When they are consumed, they are broken down into a host of chemical constituents, filtered out of the bloodstream by the kidneys, and passed out of the body in the urine. Some foods, like cranberries, are very acid in their natural state and break down into hippuric acid and other substances. On the other hand, orange juice, which is very acid when it is on the breakfast table, shows up in the urine as alkaline. There doesn't seem to be a rule about what will come out acid and what will come out alkaline.

One way to cut through the confusion is to test your own urine after eating and drinking any number of items, and see how these foods are being broken down in the body. You can buy some litmus paper or nitrazine paper (available at some pharmacies) and dip the chemically treated strips into your urine several times a day.* Soon you will begin to see if what you eat and drink has any appreciable affect on your urine.

*Nitrazine paper can be frightfully expensive—up to $18 for a small roll. There are cheaper brands, however. Ask your pharmacist to check several pharmaceutical catalogs to find a cheaper brand. R.M. Science, 111 Woodcrest Road, Cherry Hill, NJ 08034-0395, makes *ColorpHast* for under & $10.

No one has studied the issue definitively, so for the present it is impossible to say what the role of pH is, if any, in interstitial cystitis. Nonetheless, some people with IC have found that drinking water that has a neutral or slightly alkaline pH is better than drinking the slightly acidic city water. Many people also take one half a teaspoon of baking soda in water before dinner to prevent a flare in symptoms if bladder irritants are to be consumed.

NOTE: Because of the high salt content, people who have heart conditions or high blood pressure should consult their doctors before taking baking soda.

Stress Reduction

In our fast-paced, success-oriented society, we are confronted by stress at every turn. Stress may be a contributing factor in recurrent cystitis and in interstitial cystitis. It may also be a factor in the development or recurrence of cancer. In response to a very

obvious need, stress reduction programs have become a thriving industry with a wide variety of strategies and therapies to help us cope.

Responses to stress are highly individual and the methods for relieving it are too numerous to be covered here in detail. However, some of the stress reduction strategies that people with bladder disorders have successfully used are claming, non-competitive exercise such as walking, swimming, canoeing, bicycle riding (if you can ride in pleasant, uncrowded surroundings), yoga, massage and other types of body work, meditation, listening to music, visualization, hypnosis, and supportive psychotherapy. *The Relaxation Response* and *The Mind-Body Effect*, both by Dr. Herbert Benson, provide an excellent overview of stress reduction and relaxation techniques.

Of course, stress arises not only from what we do but from how we react to people, situations, and various stimuli as well. These responses are complex and deeply ingrained, and sometimes very difficult to change. Yet with hard work, stress-producing responses can be controlled. You may be able to identify these responses yourself, perhaps using the books mentioned above as a guide, and work successfully to modify them. If not, you might want to consult a therapist who specializes in stress reduction who can help you identify and manage specific stress factors.

As we pointed out earlier, the medical treatments typically work for about half of the people who try them—at least for a time—and responses to alternative therapies and self-help remedies are quite varied. Regrettably, nothing seems to work for about 5 to 10 percent of people with the severest symptoms and, ultimately, many of them look to surgery as a last resort.

MAJOR SURGERY

"One of the most difficult decisions both patients and their urologists confront in the management of interstitial cystitis is when to throw in the towel," Dr. Lowell Parsons observed in a talk to an Interstitial Cystitis Association support group in Los Angeles. Parsons was referring to the decision to remove the bladder. For patients, the decision is irreversible. If someone found a cure for the disease tomorrow, or more likely ten or more years from now, or if a drug was discovered that alleviated the symptoms reliably and substantially, people who have had their bladders removed would not be able to take advantage of the discovery. For both patients and their doctors, opting for surgery also means that they have lost the fight to successfully manage the disease.

As with any medical procedure, there is a range of outcomes. Some people, like Georgeanna, who is only thirty-four years old, are very happy with the results. "Before surgery, my whole life focused on my disease. Now I can date, sleep, swim, and go to movies without having to worry about my bladder."

Olivia had to endure a series of surgeries before she improved. "First, I had my bladder enlarged. The pain cleared up for a month, but came back again. Then my doctor diverted my urine to a bag outside the body, l but left the bladder in. I had the same pain, plus nausea all the time." Olivia finally had her bladder removed and is pain-free, although she now has occasional urinary tract infections. Nevertheless she is pleased with the result. "After I recovered from the surgery, my husband and I went on a trip to Georgia and we got there so much faster because we didn't have to stop every half hour."

Jill, who has a particularly nasty form of IC, is one of the people whose surgery was not successful. She got an Indiana pouch, but her doctor did not remove her bladder at the

time of surgery. Three months later, she had to undergo another major operation to have her bladder out. After the surgery, Jill had difficulty in catheterizing (draining) her pouch and has been plagued by kidney infections. "I wasn't warned about the potential problems attached to this surgery," she says. "I thought that I would wake up and a leg bag for urine drainage "no big deal" and sleeps better at night.

With the dramatic surgical advances that have been made in our lifetime—open-heart operations, reattachment of limbs, and delicate microsurgeries—we have come to look upon surgery as the ultimate quick fix. Yet the surgical procedures that are currently available for interstitial cystitis are exceedingly complex operations with a host of complications and post-surgical problems, and doctors who have done a number of these procedures are less enthusiastic than they once where about them.

In a 1989 survey on surgery, the Interstitial Cystitis Association uncovered two interesting facts: one, given the constant pain they had to endure, most people were happy with their surgeries; and two, people whose bladders were left in often had to return to surgery and have them removed in order to be pain-free.

In the case of interstitial cystitis, there are few guidelines available that can be used to predict who will do well afterward, so it's essential that you and your doctor evaluate your condition very carefully. Some surgeons have offered general guidelines for when surgery is appropriate. Dr. Parsons suggests that surgery should be considered "only when the bladder has really been destroyed by the disease" and surgery offers the sole possibility of improvement. Drs. Wein and Hanno feel that surgery should only be considered "for patients who have failed a multifaceted approach to conventional, conservative therapy."

In talking to both patients and doctors, we discovered that standards for when to perform surgery vary considerably from doctor to doctor. However, there seems to be general agreement that surgery is appropriate if the *true bladder capacity* under anesthesia is small (350 cc), pain is intolerable, and the symptoms are of long duration.

If you are contemplating surgery, it's also important to keeping mind that bodies and health histories are different, and what worked for one person may not work for you—the undesirable effects experienced by one person may not occur at all, or their impact may be much less for you. Before you decide to have surgery, you should be aware of all of the potential risks and post-surgical problems and be sure that you can live with them if the worst occurs. For example, some people who have certain procedures cannot urinate efficiently afterward and must do intermittent self-catheterization. The hard fact is if you don't think you will be comfortable catheterizing yourself for the rest of your life, then you should not proceed with surgery.

The following surgical procedures are the ones employed in the treatment of interstitial cystitis.

Augmentation Cystoplasty

Traditionally, removing most of the bladder and replacing it with a piece of bowel, called *augmentation cystoplasty*, has been the first choice of surgery for interstitial cystitis.

In this procedure, the diseased bladder is cut away just above the base of the bladder, leaving the trigone, the area where the bladder's nerves are concentrated, and the ureters, which enter the bladder at the top of the trigone. A piece of the bowel about 8 inches long is detached from its normal position, cut open, and folded to form a parachute-shaped pouch, which is sewn securely to the trigone. The bowel-pouch, which still has its

nerves and blood supply intact, forms an enlarged bladder that will store up to 3 cups (24 oz.) of urine.

The augmentation procedure has been favored, in many cases, because it is not a "last-resort" procedure, i.e., if it does not work, there is still another procedure—a urinary diversion—that can be done. An augmentation also leaves you closer to "normal" anatomically than any of the other surgeries, that is, urine is till collected in the enlarged bladder and is evacuated through the urethra. But not everyone who has this procedure can urinate normally. After augmentation, you will need to empty your bladder every three to six hours in order to prevent infection and kidney damage. Since the bowel segment does not have the same muscular structure as the bladder, your new bladder will probably have to be emptied with abdominal straining or the Crede maneuver. The Crede maneuver is one technique to help empty the bladder. After as much urine as possible has drained from the bladder, place your thumbs at the edge of each hip bone, and spread your hands over the lover abdomen just above the pubic bone, with the fingers touching or slightly overlapped at the end. Then press firmly on the bladder. You should avoid additional straining with your abdominal muscles, since this will force the bladder upward, counteracting the force of the downward pressure. Two variations of the two-handed Crede maneuver are the closed-hand method, using one fist instead of two hands, or using a rolled-up towel to apply external pressure to the bladder.

If these techniques are not sufficient, intermittent catheterization may be required.

Bladder augmentation works well for some people, but a few find that the frequency is relieved but pain is till a problem. In a few people, the insidious disease process of interstitial cystitis may attack the augmented bladder as well, causing the symptoms to return.[29] In this case, the bladder may need to be removed, and the urine either diverted to an external bag in a procedure called the ileal conduit, or to an internal reservoir or pouch made from a segment of bowel, called the Koch or Indiana pouch.

URINARY DIVERSIONS

Koch(Indiana) Pouch or Urinary Conduit ****Scan the picture on page 168*****

The *Koch* or *Indiana pouch* was developed for use when the bladder had to be removed because of invasive bladder cancer, but has now been done for a number of IC patients, many of whom had previous augmentation surgery. In this procedure, the bladder can be left in or removed, and an internal reservoir or pouch is made from a bowel segment. This is another form of urinary diversion. The ureters are attached to the closed end of the pouch, so that the urine drains into it from the kidneys, and the open end is drawn to the abdominal wall, where a nipple-like protrusion, or stoma, emerges from the skin or is attached to the urethra. The pouch is drained with a catheter four to six times a day.

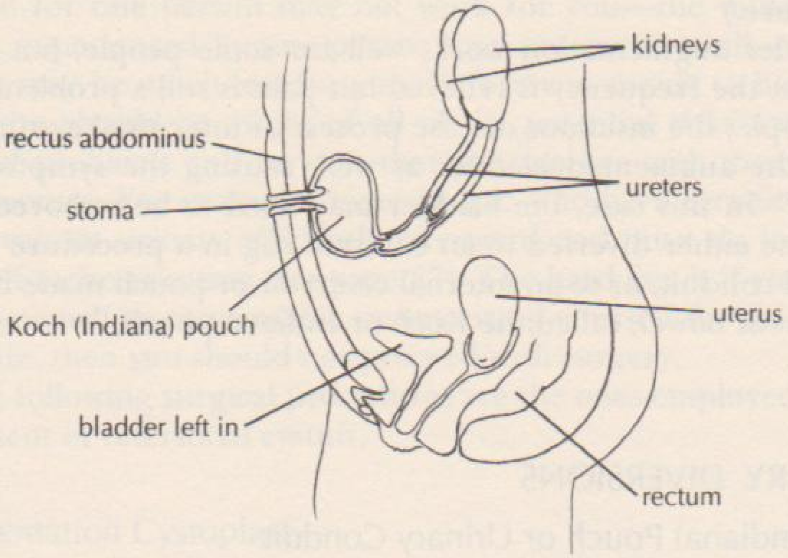
Another type of urinary diversion is a *conduit,* in which the ureters are attached to a tube fashioned from a short piece of bowel, usually the ileum, a part of the small intestine—hence the name *ileal conduit.* The conduit in turn is attached to a stoma in the abdominal wall, and urine drains continuously into a plastic bag attached to the stoma.

In both of these procedures, the bladder may or may not be removed. Unfortunately, some people with interstitial cystitis inexplicably continue to have pain in the bladder even though the urine has been diverted. To prevent this from happening,

some doctors prefer to remove the bladder (a *cystectomy*) at the time of the diversion, to decrease the likelihood of further surgery.

The hospital stay for these procedures is usually between seven and ten days. After the surgery, you will not be able to eat solid food for three to five days. You will probably be discharged from the hospital with two catheters that will remain in place for one or two more weeks: one in the urethra and suprapubic catheter that exits the skin above the pubic bone. These catheters help to make sure that no urine stands in the bladder until it is healed. About two to three weeks after your surgery, an X-ray will be taken to make sure the suture line has healed. As with most major surgeries, you will not feel like your old self for about a month, but most people feel relatively comfortable after about two weeks.

As with all major surgeries, these procedures have the potential for serious complications For bladder surgery, the most common complications are bowel obstruction, bleeding, infection, urinary or fecal leakage from the suture line, problems with general anesthesia, and complications of preexisting medical problems. In order to undergo these procedures, you need to be in good physical condition and have no major bowel or kidney problems. Betty, a psychotherapist who has severe IC, is very interested in surgery but is taking a wait-and-see approach, "I'm just trying to hold out for a few more years, until surgical techniques are better," she says, "then I'm going to get rid of the damn thing."



11. **Koch (Indiana) pouch.** This internal reservoir for urine is fashioned from a segment of bowel, and lies in the lower abdomen. You can see where the ureters are attached to the closed end of the bowel segment and where the pouch forms a stoma and emerges from the abdominal wall. In this procedure, the bladder can be left in or removed.

References:

1. Fall, M., Johansson, S.L., and Aldenforg, F.: "Chronic Interstitial Cystitis: A heterogenous syndrome," *J. Urol.*, 137:35, 1987
2. Hunner, G.L.: "A rare type of bladder ulcer in women: Report of cases," *Trans. South. Surg. Gynecol.*, 27:247, 1914
3. Held, P., Pauley, M., Hanno, P.M.,and Wein, A. J., Urban Institute Survey on Interstitial Cystitis, Workshop on Interstitial Cystitis, National Institutes of Health, Bethesda, MD., August 1987
4. McDonald, H.P., Upchurch, W.E., and Artime, M.: "Bladder dysfunction in children caused by interstitial cystitis," *J. Urol.*, 80:354, 1958
5. Held, et al., op cit.
6. Ruggieri, M.R., Hanno, P.M., and Levin, r.M.: "Nitrofurantoin is not a surface active agent in the rabbit urinary bladder," *Urol.*, 29(5):534, 1987
7. Jokinen, E.J., Alfthan, O.S., and Oravisti, K.J.: "Antitissue antibodies in interstitial cystitis," *Clin. Exp. Immunol.*, 11:333, 1972
8. Parsons, C.L., Schmidt, J.D., and Pollen, J.J.: "Successful treatment of interstitial cystitis with sodium pentosanpoloysulfate," *J. Urol.*, 130:51, 1983
9. Dixon, J. S., Holom-Bentzen, M., Gilpin, C. J., et al., „Electron microscopic investigation of the bladder urothelium and glycocalyx in patients with interstitial cystitis," *J. Urol.*, 135:621, 1986
10. Messing, E.M., "Interstitial Cystitis and Related Syndromes," in Walsh, P.C., Gittes, R.F., Perlmutter, A.D., and Stamey, T.A., eds., *Campbell's Urology* Philadelphia: W.B. Saunders, 1986, pp. 1070-1092
11. Dixon, J.S., and Hald, T., "Morphological Studies of the Bladder Wall in Interstitial Cystitis, in George, N.J.R., and Gosling, J. A., eds., *Sensory Disorders of the Bladder and Urethra* .Berlin: Springer-Verlag, 1986, pp. 63-70
12. Hanno, P.M., Levin, R. M., Moson, F.C., Teushcer, D., Zhou, Z. Z., Ruggieri, M., Whitmore, K.E., and Wein, A.J., :Diagnosis of Interstital Cystitis,: *J. Urol.*, 143:287, 1990
13. Hanno, P.M., Workshop on Interstitial Cystitis, National Institute of Kidney and Digestive Diseases, National Institutes of Health, Bethesda, MD, August 28-29, 1987

14. Fall, M., Workshop on Interstitial Cystitis, National Institute of Kidney and Digestive Disease, National Institute of Health, Bethesda, MD, August 28-29, 1987
15. Hanno, P.M., and Wein, A.J., " Interstitial cystitis, I & II," ***Am. Urol. Ass. Update Series,*** **6(9-10), 1987**
16. Sant, G.R., "Interstitial cystitis: Pathophysiology, clinical evaluation, and treatment," ***Urol. Annual*****, 3 1989, p.171**
17. Dunn, M., Ramsden, P.D., Roberts, J.B.M., et al., "Interstitial cystitis, treated by prolonged bladder distention," ***Br. J. Urol*****., 49:641, 1977**
18. Fall, M., "Conservative management of chronic interstitial cystitis: Transcutaneous electrical nerve stimulation and transurethral resection," ***J. Urol.,*** **133:774, 1985**
19. Shanberg, A. M., Baghdassarian, R., and Tansey, L. A., "Treatment of interstitial cystitis with the neodymium-YAG laser," ***J. Urol*****., 134:885, 1985**
20. Sant, G. R., "Intravesical 50% dimethyl sulfoxide (RIMSO-50) in treatment of interstitial cystitis," ***Urol. (Suppl.*****) 29 (4):6, 1987**
21. Ibid., p. 19
22. Messing, E. M., and Stamey, T. A., "Interstitial cystitis: Early diagnosis, pathology and treatment." ***Urol*****., 12:381, 1978**
23. Hanno, P. M., Buehler, J., and Wein, A. J., " Use of amitriptyline in the treatment of interstitial cystitis,: J. ***Urol*****., 141:846, 1989**
24. Wein, A. J., "Pharmacologic treatment of lower urinary tract dysfunction in the female patient,: ***Urol. Clin. N. Am*****., 12(2), 1985**
25. Fall, M.: "conservative management of chronic interstitial cystitis: Transcutaneous electrical nerve stimulation and transurethral resection,: ***J. Urol.,*** **133:774-778, 1985**
26. Gillespie, L.: ***You Don't Have to Live with Cystitis!*** **New York: Rawson Associates, 1986, p. 244**
27. Catalona, W. J.: "Bladder Cancer," in J. Y. Gillenwater, et al., ***Gillenwater's Adult and Pediatric Urology.*** **Chicago: Yearbook Medical Publishers, 1987, p. 1024**
28. Mindell, E.: ***Earl Mindell's New and Revised Vitamin Bible,*** **New York: Bantam Books, 1985, p. 80**