

With TENS, mild electric pulses enter the body for minutes to hours two or more times a day either through wires placed on the lower back or the suprapubic region, between the navel and the pubic hair, or through special devices inserted into the vagina in women or into the rectum **in men**. Although scientists don't know exactly how it works, it has been suggested that the electric pulses may increase blood flow to the bladder, strengthen pelvic muscles that help control the bladder, and trigger the release of hormones that block pain,

TENS is relatively inexpensive and allows the patient to take an active part in treatment. Within some guidelines, the patient decides when, how long, and at what intensity TENS will be used. TENS has been most helpful in relieving pain and decreasing frequency in IC patients who have Hunner's ulcers. Smokers do not respond as well as nonsmokers. If TENS is going to help, change usually occurs in 3 to 4 months.

No trials have shown acupuncture to be significantly beneficial to patients with IC. However, some patients do have reduction of symptoms and, if properly used, carries no significant risks.

Diet

There is no scientific evidence linking diet to IC, but some doctors and patients believe that alcohol, tomatoes, spices, chocolate, caffeinated and citrus beverages, and high-acid foods may contribute to bladder irritation and inflammation. Some patients also notice a worsening of symptoms after eating or drinking products containing artificial sweeteners. Patients may try eliminating such products from their diet and reintroduce them one at a time to determine which, if any, affect symptoms. It is important, however, to maintain a well-balanced and varied diet.

Smoking

Many IC patients feel that smoking worsens their symptoms. (Because smoking is the major known cause of bladder cancer, one of the best things a smoker can do for the bladder is to quit smoking.)

Exercise

Many IC patients feel that regular exercise helps relieve symptoms and, in some cases, hastens remission.

Bladder Training

People who have found some relief from pain may be able to reduce frequency using bladder training techniques. Methods vary, but basically the patient decides to void at designated times and use relaxation techniques and distractions to help keep to the schedule. Gradually, the patient tries to lengthen the time between the scheduled voids. A diary of voids is usually helpful in keeping track of progress.

Surgery

This option is considered only if an IC patient has failed all available treatments and the pain is severe. Most doctors are reluctant to operate because the outcome is unpredictable in individual patients-some people have surgery and still have symptoms.

Anyone considering surgery should discuss the potential risks and benefits, side effects, and long- and

short-term complications with a surgeon and family, as well as with people who already have had the procedure. Surgery requires anesthesia, hospitalization, and weeks or months of recovery, and as the complexity of the procedure increases, so do the chances for complications and failure.

To locate a surgeon experienced in performing specific procedures, check with your doctor.

Transurethral fulguration and resection of ulcers. Fulguration involves burning Hunner's ulcers using electricity or a laser. When the area heals, the dead tissue and the ulcer fall off, leaving new, healthy tissue behind. Resection involves cutting around and removing the ulcers. Both treatments, done under anesthesia, use special instruments inserted into the bladder through a cystoscope. Laser surgery in the urinary tract should only be done by doctors who have the special training and expertise needed to perform the procedure.

Denervation is a complicated procedure done by surgeons who have special training and expertise. Rarely used in the treatment of IC, it involves cutting some of the nerves to the bladder, interfering with pain signals. Many approaches and techniques are used, each of which has its own advantages and complications that should be discussed with the surgeon.

Augmentation makes the bladder larger, most often by adding a section of the patient's small intestine, a tube-like structure that absorbs and transports nutrients from food for use by the body. With this treatment, scarred, ulcerated and inflamed sections of the patient's bladder are removed, leaving only healthy tissue and the base of the bladder. A piece of the patient's small intestine is removed, reshaped, and attached to what remains of the bladder. After the incisions heal, the patient may be able to void normally.

Even in carefully selected patients—those with small, contracted bladders—the pain, frequency, and urgency may remain or return after surgery and the patient may have additional problems with infections in the new bladder and difficulty absorbing nutrients from the shortened intestine. Some patients are incontinent while others cannot void at all and must insert a catheter into the urethra to empty urine from the bladder.

Bladder Removal (Cystectomy). Different methods can be used to reroute urine once the bladder has been removed. In most cases, the ureters are attached to a piece of bowel that opens onto the skin of the abdomen, called a stoma. Urine empties through the stoma into a bag outside the body. This procedure is called a urostomy. Some urologists are using a technique that also requires a stoma but allows urine to be stored in a pouch inside the abdomen. At intervals throughout the day, the patient puts a catheter into the stoma and empties the pouch. Patients with either type of urostomy must use very clean, or sterile, steps to prevent infections in and around the stoma.

With a third method, a new bladder is made from a piece of the patient's bowel (large intestine) and attached to the urethra in place of the removed bladder. After a time of healing, the patient may be able to empty the bladder by voiding at scheduled times or may insert a catheter into the urethra. Few surgeons have the special training and expertise needed to **perform** this procedure.

Even after total bladder removal, some patients still experience variable symptoms of IC. Therefore, the decision to undergo a cystectomy should only be undertaken after serious deliberation on the potential outcome.

Electrical Nerve Stimulation. This surgical treatment is a variation of TENS, described previously, but involves permanent implantation of electrodes and a unit that emits continuous electrical pulses. This

relatively new procedure has variable short-term results, unknown long-term effects and, therefore, is not widely used.

Review of Treatment Options

The following is a reasonable starting point for treatment options in patients with IC

1. Education and Support, including ICA, the national support group
2. Hydrodistension
3. Antihistamines
4. Tricyclic
5. Elmiron and other oral agents
6. DMSO
7. DMSO/Prednisone/heparin cocktail
8. Oxychlorosene (Chlorpactin)
9. TENS units
10. Other therapies mentioned
11. Surgical options

Special Concerns

Cancer

There is no evidence that IC increases the risk of bladder cancer. However, the long-term effects of IC require further observation and research.

Pregnancy

Researchers have little information about pregnancy and IC, but believe that the disorder does not affect fertility or the health of the fetus. Some women have a remission from IC during pregnancy, while others have more pain and pressure during the third trimester, possibly due to the weight of the fetus on the bladder.

Working

Symptom flare-ups that result in frequent absences from work may make it difficult to get or keep a job. The Social Security Administration provides information on Social Security Disability benefits. The National Organization of Social Security Claimants' Representatives can refer you to a lawyer experienced with Social Security claims. (See "Other Resources.")

Coping

The emotional support of family, friends, and other people with IC is very important in helping patients cope with the disorder. Studies have found that IC patients who learn about the disorder and become involved in their own care do better than patients who do not. The Interstitial Cystitis Association can provide the address and phone number of the nearest support group. (See "Other Resources.")

Other coping tips:

- Find a health care team that is sympathetic, **helpful**, and receptive.
- Understand that your health care team does **not** know all the answers and may be as frustrated as you are.
- Don't become isolated from family and friends.
- Involve your family in treatment decisions.
- Do not allow IC to become the center of your life.
- Try to put IC in perspective -- worse could happen.
- Talk to other people with IC about their experiences and ways of coping.

- Trust yourself.

Research

Although answers may seem slow in coming, researchers are working every day to solve the painful riddle of IC. Some scientists receive funds from the Federal Government to help support their research, and some receive support from other sources such as their employing institution, drug companies, and the Interstitial Cystitis Association. Researchers and doctors around the country, regardless of who funds their work, may competently diagnose and treat IC.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), a part of the National Institutes of Health (NIH), leads the Federal Government's research efforts on IC. Most studies funded by the NIDDK are a result of unsolicited grant applications sent to NIH by scientists at universities and medical centers throughout the United States. Other NIDDK-funded studies result from solicitations issued to encourage increased research on a certain topic.

Suggested Reading

The materials listed below may be found in medical libraries, many college and university libraries, through interlibrary loan in most public libraries, and at bookstores. Items are listed for information only; inclusion does not imply endorsement by the NIH.

Other Resources

American Foundation for Urologic Disease
The Bladder Health Council 300 West Pratt Street, Suite 401 Baltimore, MD 21201
410/727-2908 or 1-800-242-2383

American Pain Society
5700 Old Orchard Road Skokie, IL 60077
7081966-5595

American Uro-Gynecologic Society
401 North Michigan Avenue Chicago, IL 60611-4267
312/644-6610

International Pain Foundation
909 Northeast 43rd Street, Suite 306 Seattle, WA 98105-6020
206/547-2157

Interstitial Cystitis Association of America, Inc.
P.O. Box 1553 Madison Square Station New York, NY 10159-1553
212/979-6057 or 1-800-ICA-1626

National Chronic Pain Outreach Association
7979 Old Georgetown Road, Suite 100 Bethesda, MD 20814
301/652-4948

National Kidney Foundation
30 East 33rd Street New York, NY 10016

212/889-2210 or 1-800-622-9010

National Kidney and Urologic Diseases Information Clearinghouse
3 Information Way Bethesda, MD 20892-3580

National Organization of Social Security Claimants' Representatives
6 Prospect Street Midland Park, NJ 07432
201/444-1415 or 1-800-431-2804

Social Security Administration
write or call your local office (found in the telephone book under U.S. Government, Department of Health and Human Services) or call 1-800-234-5772

United Ostomy Association
36 Executive Park, Suite 120 Irvine, CA 92714
714/660-8624
