URGE INCONTINENCE: A TIME FOR BLADDER TRAINING

The term urge incontinence describes the compelling desire to urinate and the inability to delay voiding long enough to get to a toilet. It is a very common complaint. Some people have unstable bladder contractions many times per day. Often sufferers restrict their fluid intake in an attempt to avoid the frequency, or they empty their bladders often to avoid accidents.

Neither of these methods is helpful. Restricting fluids is dangerous and does not give the bladder a chance to fill up and begin to work correctly. The same thing happens with frequent emptying...the bladder never adjusts to holding much urine and thus the problem gets worse. In fact, many of the ways people now cope with urge incontinence encourages unstable bladders. The bladder is a muscle, which can be strengthened with training to reduce some of the problems of urge incontinence.

Like all remedies for incontinence whether surgery, drug therapy, artificial implants, Kegel exercises, or bladder training, you must first know the type and cause of your incontinence before you can find the solution. Those most likely helped by bladder training are people with unstable bladders from an apparent cause who are experiencing a condition which has gradually worsened. People with multiple sclerosis, stroke, and spinal cord injuries are not likely candidates. So, consult your doctor. Only he or she can tell you if your urge incontinence can be helped by bladder training.

A bladder training program is fairly simple and straightforward. Over a period of time the bladder is retrained to hold

INTERSTITIAL CYSTITIS: A DIFFICULT CONDITION

Interstitial cystitis is a disease which is both difficult to diagnose and to treat. Although far more common in women, the condition can occur in either sex and at any age. Most people with this disease of the bladder experience incontinence, usually frequency both day and night. The most distressing symptom is pain, which occurs both on bladder filling and especially at the end of voiding (called micturition).

Most people with interstitial cystitis do not have infected urine, and bladder lesions are often not evident on "routine" cystoscopy, especially when the physician is not specifically looking for this problem when performing the test. "Failure to suspect the presence of interstitial cystitis is the commonest reason that the diagnosis is missed," states Campbell's Urology, a widely used urology textbook. The same text continues: "It is characteristic of these patients that they have consulted many physicians, have received many diagnoses, have been treated in many ways, operative and otherwise, all without relief."

Because of these difficulties, it is important that the patient experiencing pain during bladder filling, and at urination, become an informed medical consumer. Questions and statements such as the following could be of help:

"I think the pain I'm experiencing is abnormal. I need to find the cause and consider treatment options."

"Can you refer me to a specialist who is skilled in diagnosing interstitial cystitis? I feel because of the pain I'm experiencing, the possibility of this condition should be explored."

The patient who pinpoints their symptoms and suggests looking at the possibility of interstitial cystitis as the cause heightens their chances of a correct diagnosis.

(Continued on page 2.)

ONE VOICE, an editorial

Many people find it difficult to ask for a second medical opinion. The Foundation receives a constant flow of letters confirming this statement. Daily, members write telling us about their problem, what their doctor has recommended and asking us to cast our vote. We can't. We are not medical practitioners and without the data from a complete medical examination and the appropriate tests, no one can give you a sound second medical opinion.

Putting the problems of extra costs, tests, and time aside, what are the barriers to a second opinion? Perhaps you are afraid to hurt the feelings of a caring physician who you have relied upon for many years. However, most physicians we talk to welcome a second opinion, because more information and confidence helps a patient firmly decide on a course of action and enhances the patient's ability to comply with treatment. How the patient approaches the second opinion, not the fact that they want one, may be crucial. For example, no one would take offense at the following statement: "you've been such a help to me all of my life, but this problem bothers me so much that I'd like to seek a second opinion."

Remember, the purpose of another opinion is to help YOU, the person living with the body that needs fixing, decide what action to take. The second opinion has nothing to do with your respect for the physician who has been treating you.

Another reason people don't ask for a second opinion is that they didn't understand the first one! If you see yourself in this position, then the person to ask for the next opinion is you. That's right. You can marshal yourself into the nearest medical library or ask your physician to borrow his or her medical literature related to your

(Continued on page 3.)
INTERSTITIAL CYSTITIS (continued)

Obtaining the correct diagnosis is not the only problem for people with interstitial cystitis. The causes are still being debated and effective treatments sought. There are many theories as to the causes of the problem. One theory is that interstitial cystitis is an autoimmune disease. Simply put, this means that the diseased tissue in the bladder causes the bladder to produce antibodies against itself, which can in turn cause more damage to the bladder.

Another theory is that interstitial cystitis is caused by multiple factors. Perhaps there is something abnormal in the urine or the bladder wall of persons with the disease. Yet another possibility is that for unknown reasons certain people are affected by an agent occurring normally in the urine.

Whatever the cause, most urologists agree that successful treatment of this disease is difficult. Treatment possibilities include drugs, treatment of the bladder directly, denervation and bladder substitution. Some patients have found relief with anti-inflammatory drugs which also contain a pain reliever. The bladder itself may be treated by distending it under anesthesia and injecting the bladder wall with a pain killer. Another technique which has been tried is to interrupt the innervation to the bladder. A surgical procedure severs the nerves, thus alleviating the sensation of pain. Another surgical approach, called enterocystoplasty, completely replaces the bladder. The bladder is removed and in its place the surgeon constructs a new bladder made from the patient's intestinal tissue. Bladder substitutions are a major surgical procedure with all the risks of possible complications. It is considered by most practitioners to be a treatment of last resort.

Like incontinence, both professional and lay attention is beginning to be focused on interstitial cystitis. A recent study found that on average, a span of seven years occurred between the onset of symptoms and the correct diagnosis of interstitial cystitis. Unfortunately, many patients have been led to believe that their problem was an emotional one, perhaps stress related, before a correct diagnosis was made.

As the groundswell of support in the medical community for research into causes and treatment protocols continues, patient care will surely improve. Another sign of hope for the patient is the establishment in 1984 of the Interstitial Cystitis Association, Inc. P.O. Box 1553, Madison Square Station, New York, NY 10159; P.O. Box 15123, San Diego, CA 92115.

URGE INCONTINENCE (continued)

more urine and empty at appropriate times. This means, learning to suppress the inappropriate urge to void when the bladder is not yet full. First you must do some planning, or establish a baseline. For several days you need to fill out a chart with the following information:
1. time that you void
2. the amount of urine voided
3. the time and type of bladder control accident

Once you have your own chart, you and your doctor will be able to see how long the intervals are between voids.

With this information, you can now set goals to increase your fluid intake and increase the time between voids. The outcome of these goals is that your bladder's capacity will increase and you will train it to signal you only when it is really full, not just when the bladder muscle decides to have an unstable contraction. Along the way, you will learn to distinguish between the sensation of a full bladder and a contracting and irritable bladder.

During this training time you should avoid alcohol, tea, coffee, and all caffeine-based beverages. For many people these are known to be bladder irritants. Once you have reached the level of three to four hours between voiding, you can experiment with these beverages to see which of them your bladder accepts.

Now we are ready to begin.

There are two common approaches to bladder training. One method attempts to train you to defer voiding whenever you feel the urge. The other method helps you learn to void only at fixed intervals. Many people report a preference for the deferred voiding approach. Remember, you must still keep the chart in order to identify both progress and problem areas.

To begin deferred voiding training, whenever you feel the urge to void, attempt to put off using the washroom. At first you may only be able to do this for a minute or two. However, you will find that once the contractions pass, you may be able to delay even longer. There are many tactics for delaying. Deep breathing may help, counting backwards from one thousand, or contracting your pelvic floor muscles. For many years you may have been responding to this urge, so don’t expect too much too soon. Remember each day you are gaining on your goals, to suppress contractions, to stretch the walls of the bladder muscle, and to learn to distinguish when your bladder is truly full and when it is giving you a false message.

Of course, another habit that you will have to break is going to the bathroom before you leave your home “just in case.” This “just in case” method also deprives the bladder of learning to hold its true capacity and slows down your progress. Each week, a longer period between voiding should be the goal until your voiding pattern becomes normal. For most people the time between voids is between three and four hours.

Like all exercise plans, bladder training is only as successful as your determination to stick to it. It often helps to establish rewards for your efforts and to penalize yourself for not sticking with your goals. A movie, or withdrawal of a favorite television program, might be a good bargain with yourself.

A second type of program for stretching the bladder muscle is timed voiding. After establishing the baseline, the patient goes to the restroom at rigidly fixed intervals. Gradually, these intervals are increased. Obviously with this method it is important to space your fluid intake evenly throughout the day. Many long term care facilities use this method to help their residents reestablish bladder control, especially those patients who may tend to forget to use the washroom.

Whichever program is used, three months of record keeping should show marked improvement in not only your bladder’s capacity, but also in a decrease in the number of bladder control accidents. Many people also report a decrease in nocturia or nighttime voiding.

Some people may have a few additional hurdles to overcome. They may have become sensitized to certain cues such as running water. These cues set off the urge incontinence and need to be unlearned. Desensitizing oneself to cues is done in the same way as other bladder training. After emptying your bladder, expose yourself to the cue and begin to use all of the delaying techniques which you have already learned. Once you have mastered this, do the same thing with a partly filled bladder and then with a completely full bladder, until the cue no longer causes the urge to urinate.

Managing urge incontinence with bladder training programs is becoming more widely used. For those who do not succeed after faithfully following the program, there are other remedies which your physician can offer you, among them drug therapy and surgery. The problem of urge incontinence, like all types of incontinence, can be treated and managed if you and your physician stick with it until the problem is solved.
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ONE VOICE (continued)

problem. With the help of a medical dictionary, a layman can gather much information from medical texts.

Another well-founded fear is that the second opinion will be diametrically opposed to the first. What does the patient do then? First, it helps to realize that medicine can be somewhat of an art. It is not always pure science. The solutions aren’t always straightforward. The causes of many physical problems are still unknown. Therefore, if there is disagreement about the cause, there will surely be disagreement about the correct treatment. If you run up against this situation, one solution is to get both physicians to agree on another expert for you to see. If they choose the same expert, they will accept the outcome.

Speaking of experts, many people are confused as to who to consult for a second opinion. One solution is to find out who is the leading authority in your region. The old adage “practice makes perfect” applies to the practice of medicine also. A physician who has had plenty of experience with your condition should be a valuable resource as a second opinion.

Getting a second opinion, is simply getting more data to make the best choice for yourself from the options available. If you feel the need for a second opinion, please seek it. We think you are worth it!

THANK YOU! Editor’s Note: This issue of the *Informer* was underwritten by an educational grant from Principle Business Enterprises, Inc., makers of Tranquility Products. The Simon Foundation does not endorse specific incontinence products or medical treatments. Inclusion of our Thank You column in no way implies endorsement. The following column was prepared by Principle Business Enterprises, Inc.

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LETTERS TO THE EDITOR

Dear Simon Foundation:

I’ve ordered one of your Sample Paks of products and hope to establish home delivery as I find it most embarrassing to buy disposable products at a drug store. I am under a doctor’s care and have been using clean, self-catheterization for the past three years, but still leak between catheterizations. I have tried an indwelling catheter with leg bag. Although there is no leakage, it can be uncomfortable at times. If possible, I would like to hear from others with their views on using catheters. You may use my name and address.

Charles Renner
P.O. Box 604
Apopka, Florida
32703

Dear Ms. Hartley:

I’m a twenty-nine year old male with severe urinary incontinence. Recently I began to use adult diapers, and not long ago, after using a public restroom in a large department store I was stopped for shoplifting. It seems someone from the store heard me changing in the restroom stall. After searching my gym bag which I was carrying, I was released.

The adult diapers work great, even under my street clothes, and I’d like to continue using them without having problems in the future. Any suggestions?

D.H.

Dear D.H.

I’m at a loss to comment and need reader support. However, thank you for sharing your experience. Others might want to carry your letter in their billfolds. If the same thing should happen to them, they could show the letter to the store personnel.

Dear Informer:

If you choose to print my experience, use my name and address. I would gladly correspond with others. I am constantly suggesting to others with incontinence problems that they continue to view each day with good humor, imagination, and a zest for living. Then last summer, I had a good reason to test my own “good humor”——

The occasion was a birthday party. Like others, I volunteered to bring goodies. When I pulled up in my car and started to get out with my heavy grocery bag, I noticed the honoree snapping pictures of all the guests as they came along. Hey great, I thought, and stepped out hugging the bags in both arms. What I didn’t know was that as I had picked up the groceries, I’d also caught the hem of my skirt along with the bag. For my audience and the camera, there I stood, unknowingly, with a full four inches of skirt raised, showing a clear look at my pink rubber incontinence bloomers. Radiantly pink, with shrilled elastics just above the knees. Once I realized my predicament I outmatched even their pink color. I was crimson!

Isn’t it surprising that in just moments we all kidded and laughed? After a brief admission of my condition, little was ever said. Those who had been friends are still friends. I’m told I’ve gained respect, not lost it, for my outlook and good sense of humor.

Ms. Patricia Manning
P.O. Box 118
Georgetown, CT. 06879

Dear Informer:

Thanks for sharing your experience with others. We hope you receive plenty of letters as we know you’ve been wishing on more pen pals for some time now.

Dear People at the Simon Foundation:

I look forward to getting the Informer and seeing the new things that are being done. One thing I wish you would do is to ask some manufacturer to design rubber pants and other things in extra large sizes. Don’t they think that fat people have trouble with incontinence? In fact, I don’t go out. I’d like to see someone make an extra large so we could go off and do a little shopping.

M.F.
in Connecticut

Dear Simon Foundation:

Can you suggest to the manufacturer the use of small discrete lettering as an act of consideration for the purchaser? I dislike having to carry a well-marked box through the store.

Illinois

DEAR ALL:

The manufacturers all read this newsletter, so your pleas will be heard by the right ears. Connecticut, do try to meet them part way by working on your weight problem. Many people find their incontinence problems lessen with weight loss.

A WORD ABOUT MEDICATIONS:

Whenever your doctor gives you a prescription, be sure to finish it even if your symptoms are no longer present after taking some of the medication. Also, whenever visiting your doctor it is always helpful to carry a list of all the medication you are currently taking, including the dosage. Remind your physician of this list whenever he or she is prescribing a new drug.