Experimental Electrical Stimulation for Neurogenic Bladders

Something happened several years ago in Hungary which may bring continence to many Americans someday. Dr. Frances Katona of the Institute of Neurosurgery in Budapest theorized that people with neurogenic bladders could be helped by electrical bladder stimulation.

Bladder control is dependent on sensory impulses traveling back and forth along the nerve pathways. These signals report fullness, control bladder contractions which force the urine out, and open and close the sphincter muscles. These nerve pathways do not work correctly in people with neurogenic bladders. The condition can be caused by multiple sclerosis, stroke, spinal cord injuries, and spina bifida, to name a few of the common causes.

But suppose these nerve pathways could be "re-educated." Back in 1958 Dr. Katona decided that he could do just that by using indirect electrical stimulation. By means of a special catheter, saline solution is introduced into the bladder. Then a very low level electrical current is passed through the solution. The solution helps to deliver the electrical current evenly to the bladder wall. This stimulation activates those bladder receptors which are still capable of functioning. Eventually, these impulses of bladder fullness reach the brain. Thus the person "relearns" the feeling of bladder fullness.

Over a 15-year period Dr. Katona selected 420 patients to be treated. Fully 75% of them acquired, or regained, the ability to control their urination. Once he began treating a wider range of patients, many of whom were extremely difficult cases, the success rate was still about 50%.

But Hungary is a long way from Main Street America. And, often times new treatments don’t spread from coast to coast, let alone across the Atlantic. Perhaps there is hope for this modality however. The Journal of Urology, July, 1986, reports on an American follow-up to Dr. Katona.

Refuting Irrational Ideas

Editor’s Note: The following is an excerpt from the chapter “Strategies for a Full Life” by Ronald H. Rosenstey, Ph.D. and Steven M. Toscan, Ph.D. from Managing Incontinence: A Guide to Living with the Loss of Bladder Control.

People constantly engage in self-talk, your internal thought language, sometimes called cognition. These are the sentences with which you describe and interpret the world. If the self-talk is accurate and in touch with reality, you function well. If it is irrational and untrue, then you experience anxiety, depression, and emotional disturbance. This sentence is an example of irrational self-talk leading to the feeling of hopelessness: “I can’t bear to be alone.” No physically stable person has ever died merely from being alone. Being alone may be uncomfortable, undesirable, and frustrating, but you can live with it, live through it, and use options to change it.

Another example of irrational self-talk: “I must never have an accident in public. If I do, I’m a failure as a person.” The words “must never” allow no possibility of a flaw. Should the inevitable occur, you label yourself rotten — all on the basis of a single incident.

Irrational ideas may be based on outright misperceptions or perfectionist shoulds, oughts, and musts. Inaccurate self-talk such as “How terrible to be rejected” is fear-producing in comparison with “I find it unpleasant, and momentarily awkward and regrettable when I am rejected.”

Albert Ellis, a psychologist, developed a system to attack irrational ideas or beliefs and replace them with realistic statements about the world. His basic notion is that emotions have nothing to do with actual events. In between the event and the emotion is realistic or unrealistic self-talk. It is the self-talk that produces the emotions. Your own thoughts, directed and controlled by you, are what create anxiety, anger, and depression.

At the root of all irrational thinking is the assumption that things are done to you. Nothing is done to you. Events happen in the world. You experience those events (A), engage in self-talk (B), and then experience an emotion (C), resulting from the self-talk. A does not cause C; B causes C. If your self-talk is irrational and unrealistic, you create unpleasant emotions.

Two common forms of irrational self-talk are statements that “catastrophize” and “abjectize.” You catastrophize by making terrible, nightmarish interpretations of your experience. A momentary leakage will become a pool of urine. The emotions that follow catastrophizing self-talk tend to be awful, for you are responding to that very description of the event. Irrational self-statements that “abjectize” often include words like should, must, ought, always, never. Events have to be a certain way, or you have to be a certain way. Any deviation from that particular value or standard is bad. The person who fails to live up to the standard is bad. In fact, it is that standard that is bad, because it is irrational.

Dr. Ellis has suggested ten irrational ideas. Think how they can be related to incontinence problems.

- I must have love and approval from peers, family, and friends.
- It is horrible when people or things are not the way I’d like them to be.
- I should fear anything that is unknown or uncertain.
- It is easier to avoid than face life’s difficulties.
- You need something other or stronger or greater than yourself to rely on.
- The past determines the present.
- Happiness can be achieved by passivity.
- You are helpless and have no control over what you feel, experience, or do.
- When people disapprove of you, it

continued on back page
Dear Informer:

I have an eight year old daughter who was born with a congenital anomaly of her urinary tract which has resulted in complete urinary incontinence. She had her ureters relocated at three months of age and six months ago an attempt was made to reconstruct her bladder neck to give her some continence. The operation was not a success and she still remains incontinent. Further reconstructive surgery will not be attempted for at least five years.

In the meantime she wears extra large size Pampers. By next year those will no longer fit and I am at a loss as to what she will wear. I need to find a product that will be socially acceptable and comfortable. It seems as though the manufacturers of incontinent products have forgotten about the thousands of handicapped children who need these products. We have tried many other types of diaper products and they are huge on a child.

I would appreciate corresponding with others who might have a child who is incontinent to see if they have discovered any products that might be helpful. I would also appreciate hearing from older females who may have grown up suffering from incontinence. As my daughter grows up, I am wondering how she will cope in society successfully. I want to be able to help her as much as possible. At the present time she is like any other eight-year-old child, the only difference is that she has to wear diapers. She doesn’t think it is so bad as she has never known it to be any other way. I do know that the only time she will not feel this way. Any help your readers can give me will be greatly appreciated.

Anita Norman
50 Russell Road
Hurlay, New York 12443

Dear Mrs. Norman:

If only we could clone you and your attitude to be the parent of every child with incontinence problems. I hope you are wrong about one thing though. I hope your little girl does not change her attitude about a birth anomaly. I noticed you didn’t use the word “birth defect.” Another hurray for you! “Defective” is a word for a new appliance that doesn’t start when we flip the switch... the word should never be applied to a human being.

Dear Good Luck:

You seem to express the consensus of most who wrote. One other tip is to spread your protection into each of your bags so if the airline loosens a bag you aren’t stranded.

Dear Editor:

I suffered with incontinence for many years and did not seek medical help. I was sure I needed surgery and I wasn’t ready for that. Finally it got so bad that I did consult a urologist. To my surprise I found that I did not need surgery, that I was having spasms. One tiny little tablet per day and I’m normal.

Urge your readers to consult a urologist. He is trained to treat this medical problem. Also — you may get good news as I did.

Please pass it on.

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One Voice... an editorial

Not letting incontinence get you down or keep you closeted in your home is often the subject matter of this editorial column. Loyal readers all know why I harp on this theme: “life is short,” “you are unique and have something unique to offer,” and “you are needed to help improve the world around you” — all variations of the same theme. Last night’s TV newscast added another variation of the theme. It stated that only 55% of Illinois voters were expected to turn out for the primary election.

Don’t Americans know there are places in the world where people risk death trying to escape to come to this country in order to have the privilege to vote? Maybe they do not realize that in some countries this newsletter’s editorial could be censored and the writer jailed. Perhaps they think people in Russia listen to Radio Free Europe whenever they please, and that Russians just have a peculiar habit of keeping their drapes drawn.

I was lucky. I grew up knowing these things almost first hand. My grandfather crawled across the border of Communist Latvia under gunfire, with only the shirt on his back, seeking the promise of America. He was rabid about our freedoms, especially the freedom to vote. And, with no apologies, I must admit that I inherited this passion for the right to vote. Whatever the issue, I’m happy they want my opinion, and I never want to even have to think about what life would be like if you and I, Joe Average Citizen, weren’t asked to vote.

Don’t get me wrong, this editor has great empathy for the emotional distress of incontinence, the fear of having an accident in public, and all the trials and tribulations associated with the problem. But if there ever was a day to overcome your fears, it’s election day.

Get with it incontinent America. There are men and women out there running for office. The winners are going to be called upon to decide important health care, Medicare, and reimbursement issues. These are issues which personally affect us all. These same winners will influence our foreign policy, national defense, education, and social services. So study the issues, pay attention to the candidates and GO VOTE.

Today I witnessed a “happening” at the polls. It occurred in a church lobby polling place. The clock showed five minutes to closing and the lines were still long. Tired and wet commuters had just made it to the door with the lady bringing in the flag before the real downpour let loose. Through the large window a lone young woman could be seen giving up the struggle with an umbrella and beginning the dash up the long, steep walk to the church door.

She arrived, conferred with the official at the door, and out she dashed again. Puzzled, people in the slow-moving line stared in fascination as she returned to her car, placed a walker before her elderly father and helped him from the car. Slowly, he began to inch his way up the walk and it became painfully obvious to all of us that this was going to be at least a ten minute ordeal. At this moment a bureaucrat type, clearly the “leading lady,” ordered the doors locked and the polling place officially closed. The stunned official at the door argued vehemently, pointing out the church clock was fast. He was quickly hustled by the citation of a supposed rule that the flag must be flying when voters enter the polls, and since it wasn’t, the polls were closed. It was one of those inane, awesome statements that a bureaucratic leader occasionally seem capable of making — the kind of verbage that leaves even the most casual observer struck dumb.

In the dead silence that followed, the stranger in front of me handed me his Yuppies Gucci briefcase, took the flag from the table by the door, and walked out into the storm. Not even Norman Rockwell could have improved on the picture of the young man proudly holding the flag aloft in the driving rain while the old man passed.

So don’t worry America. There are many people like these two men who are keeping the voting privilege alive so that it will still be there for the rest of us. Please readers, make the effort to vote.
Dear “Pass it on”:
I suspect most of our readers think I’m a complete n00d on this subject, but obviously you don’t. I happen to agree. SEE YOUR DOCTOR can’t be said often enough or as well as you did. Thanks for writing.

Dear Editor:

Pursuant to your “Opinions Sought” questionnaire in the fall edition, I would like to see more articles about dealing with incontinence or bedwetting. I have lived with it for 55 years now, and I realize that if you were to rate the various types of incontinence on a scale of 1 to 10, enuresis would probably barely qualify as a 1. However, to those who live with it, it is a condition which must be factored in when considering many activities. And, since it is so easy to conceal in the privacy of your home, meaningful figures on those so afflicted are difficult to come by. In their book “A Parent’s Guide to Bedwetting Control”, Drs. Nathan H. Azrin and Victoria A. Basile, cite figures that indicate 2% of the adult male U.S. population are bedwetters. Figures gathered from institutions like orphanages show that males are twice as likely as females to be affected. If their data is correct, that’s well over 3 million afflicted with the problem in the U.S. alone. Each one of them has had to devise methods of dealing with it.

Clive M. Beckwith
13305 S.W. 109 Place
Miami, FL. 33176

Dear Mr. Beckwith:

We certainly appreciate our members. When we ask them to participate in research or have their opinions they respond. I disagree that bedwetting would hardly rate a 1. It is very stressful for many people, especially children who are often unduly punished. Like all incontinence, bedwetting should be explored with a physician to find the reason.

Dear Informer:

I have been incontinent for a number of years and am still learning how to manage the problem. Your book, Managing Incontinence is the most useful and educational I have found. However, I get the impression that many people with this problem do not regularly wear protective garments. They try to make it to the toilet before they have an “accident”. Or they wear only minimal protective garments that require immediate changing. My approach is more pragmatic. I wear diapers all the time. I would rather have the protection and not need it, than be sitting in a puddle or desperately running for the bathroom. As a professional barrier, my attitudes and approaches to a problem are straightforward. I like simple, practical solutions.

So far, the only product that has met my needs is plain old cloth diapers with pull-on waterproof pants. Many people object to the “bulk” of diapers and I was no different. Initially, I was extremely self-conscious. To me, my jean bulged ridiculously, I wondered how anyone could NOT notice. I quickly learned, however, that no one else noticed anything unusual. Incontinence is still a largely unknown condition to the majority of the public. The thought that an adult is wearing diapers simply does not enter peoples’ minds.

I don’t consider incontinence a disability and see no good reason why it should restrict my activities. To me, it is an occasional inconvenience. It is sometimes inconvenient to carry spare diapers or find a place to change them. However, there are some advantages. When I travel I don’t have to find a gas station every hour or two! This fact sometimes causes friends who ride with me a good deal of consternation. Unless reminded, I often keep driving until the car needs gas, not noticing the discomfort of the person next to me.

In your book you talk about euphemistic terminology used by people to refer to bodily elimination functions. However, I also notice that people who suffer from incontinence use their own set of euphemisms. For example, the frequent use of the term “accident”. I wet my diapers. It is no “accident.” If I don’t change them before they leak, it is no “accident.” Just stupidity. Another cute term is “disposable incontinent pants.” Who do we think we are fooling? Why not call them the disposable diapers they are?

I would like to correspond with other people who have this problem and hear how they manage. Learning to live with incontinence has been a trial and error process for me. Spreading information through organizations such as yours is a far better way.

Jeffrey A. Lersch
3252 Nottingham Road
Ocean Springs, MI 39564

Dear Jeffrey:

I wish we had room to print your whole letter because of the practical approach you take. It seems you know how to make the best of everything.

Lemons can be turned into lemonade, can’t they?

All of us can find a good outcome in any unfortunate life event, not just incontinence, if we try. Attitudes are the real disability.

Recently, a dear friend of mine and her college age daughter on the way home for Thanksgiving, were almost killed by a drunk driver. Instead of returning to school, Steffie spent the next several months returning to surgery. Some might have sunk into depression. Steffie chose to return to her high school and give testimony to the awful results of drinking and driving.

Suitably, I’m sure she prevented several teenagers from driving the highways while drinking. Lemons can be turned into lemonade. It takes creativity, courage, and the right attitudes.

Dear Editor:

On January 1, 1987 I wrote a letter detailing an embarrassing accident at a grocery store, and my resolve to come out of the “water closet.” Well it’s been a year since you printed my letter, and I’d like to tell you what my year has been like.

Deciding that I would give up bowing to “King Fear” wasn’t enough for me. I had to find a way to put my decision into action. I started by telling some of my coworkers and bosses. Some knew and some didn’t, but not one person rejected me because of my disability.

As an entertainer, confidence is the name of the game, so my next step was to learn to change costumes in the communal dressing room without being embarrassed (or at least I tried behaving in an unembarrassed manner). I practiced changing clothes at the YMCA, where I workout, in front of the other men in the locker room — like a normal person — rather than waiting until it was empty. Lo and behold — no one cared! I practiced for a month before trying this at work. Once again the result was the same: not a word was said.

But I was treated differently than before. I was treated with more respect by my colleagues because, as one person said, I no longer behaved as if I was trying to hide something. I have gained something else as well: self-respect. I feel free to be who I am, and become more than I was. Don’t misunderstand; it hasn’t been easy. I had to make conscious choices to behave normally in difficult situations, but the boost to my self-esteem is worth it. I am worth it.

In addition to acting, I am now also teaching at an elementary school. My principal and I are working on a science and health project to help the kids understand disabilities (including incontinence and enuresis). We feel that this will not only teach them about their bodies, but also help the ones who wet their beds feel better about themselves, and fear ridicule less if anyone finds out.

If you choose to print this please use my full name and address. The letters I received last time were a help in my progress toward a more mature attitude, and I have gained some lasting friendships. I would love to correspond with other incontinent people to our mutual benefit.

David C. Maruno
5218 Ansonia Ct.
Orlando, FL. 32809

Dear David:

Your letter reminded me of one of my favorite quotes from Theodore Roosevelt: “Do what you can, with what you have, where you are.” We wish on you tons of letters!

THANK YOU. Editor’s Note: This issue of The Informer was underwritten by an educational grant from Johnson & Johnson.
Simon Says

**DECUBITUS: A Compendium of Prevention and Treatment of Pressure Ulcers** is a brand new publication directed at the healthcare professional. A one-year subscription for $15.00 can be obtained by writing DECUBITUS, Printer's Square, 600 South Federal Street, Chicago, Illinois 60605-9978. The publication is a resource for all healthcare professionals interested in the prevention and treatment of pressure ulcers.

**REMINDER...** When you want to change your name and address, or correct a spelling mistake, please be sure to include your membership number which appears on the mailing label of this issue of The Informer.

**TAKE ACTION...** Many of you write to us when you see an article on incontinence in your local newspaper or a magazine. We sincerely appreciate this input. We encourage you to also consider writing the author of these articles and thanking them for helping to educate all of us about cure, treatment, and management of incontinence.

**A NEW BOOK...** Aging with a

Irrational Ideas continued

- You shouldn't have to feel pain: you are entitled to a good life.
- Much of the difficulty in uncovering irrational self-talk results from the speed in which thoughts occur. Self-talk has a reflexive, automatic quality. However, once thoughts are slowed down, you can assess their rationality and impact.

Below are five steps (A through E) to disputing and eliminating irrational ideas. Start by selecting a situation that consistently generates disturbing emotions in you.

A. Write down the facts of the event as they occurred.
B. Write down your self-talk about the event.
C. Focus on your emotional response (anger, depression, worthlessness, fear, etc.)
D. Dispute and change the irrational self-talk.

1. Select the irrational ideas you wish to change (e.g., “It is unfair that I have to suffer with incontinence”).
2. Is there any rational support for this idea? (The problem must be endured and dealt with because it happened. It happened because all conditions existed necessary to make it happen.)
3. What evidence exists for the falseness of this idea that I had to suffer with incontinence? (There is no guarantee that says I should not have pain or problems through incontinence — no laws of the universe. I can experience any problem for which the necessary conditions exist. Life is not fair. Life is a sequence of events, some of which are inconvenient and painful. If problems occur, it is up to me to solve them. No one is special. Some go through life with relatively fewer problems than I. This probably traces to luck or decisions I have made that contributed to the necessary condition for my problems. Just because I am incontinent does not mean I have to suffer. I can take pride in the challenge of a creative solution. This may be an opportunity to increase my self-esteem.)
4. Does any evidence exist for the truth of this irrational idea? (No, my suffering could stem from self-talk or how I have interpreted my incontinence. I have convinced myself that I should be unhappy.)
5. Sometimes focusing on the “worst” alternative helps you plan ahead. (I could be deprived as a result of incontinence of various pleasures while I deal with the incontinence. I might feel inconvenient. I might never solve the problem and accept the consequences. Others may not approve of how I am behaving and I could be rejected.)
6. Is there anything positive that you can find in this experience? (From incontinence, I might learn to tolerate frustration or improve my coping skills.)
E. Substitute alternative self-talk now that you have examined the irrational idea and compared it with rational thinking. (I can accept painful situations when they arise from my incontinence. Facing problems from incontinence is more adaptive than resenting it or running away from it. I feel what I think. At worst, with incontinence I will experience inconvenience, regret, and annoyance — not anxiety, depression, and rage.)