

## *Introduction*

I had become a prisoner of My Own Private Bathroom, a sanctuary and source of salvation in my life, and I was desperate to be released from a life-long sentence.

For over 40 years, since I was 13 and at a familiar summer camp, I could not urinate easily while other people were nearby in a bathroom. It didn't matter whether it was a women's public restroom, the home of my friends and relatives or even in my own home if visitors were close by or someone was waiting for me. I simply could not "go" at will when I needed to, no matter how hard I tried.

Despite my limitations in being unable to urinate "like everyone else," I resisted my temptation to surrender to paruresis. Instead, I continued to try and live my life as best as I could. I simply rationalized away my condition and accepted my fate and circumstances. "*Some people,*" I told myself, "*are in wheelchairs, while others are blind. They manage; you can, too.*"

In the most desperate of times, I prayed.

### *The mind-body connection*

After my initial episode, my fears about urinating and the consequences of not being able to intensified. The urologists to whom my well-meaning parents took me performed a variety of medical tests, some of which were quite painful. No physiological cause was ever found. One urologist reassured my mother by telling her, "*The problem will go away once she gets married.*" Another placed me on anti-anxiety medication to help relieve stress.

The pattern of avoidance of bathrooms had set in, and my condition essentially took on a life of its own. When I was heavily stressed and/or afraid, the tension I felt was channeled to and registered in my pelvic region. It became the repository for the expression of powerful emotions: anger, fear, even excitement. The sphincter muscles, which govern the release of urine, shut down, rendering it impossible for me to urinate except through catheterization or in the privacy of my home without anyone present.

### *Bathroom blues*

The interior of my mind contained a constellation of restrictive thoughts that fed upon each other. Entering a bathroom, I would constantly think: "Who will see me? Who will hear me? Who is waiting to use it? And what might they be saying about me?" My heart pounded whenever I even dared to approach. The anticipation of failure before I entered a restroom set the tone for my experience. When I could not perform, I would beat myself up emotionally.

On a day-to-day basis, I coped for years by holding in my urine for long periods, refrained from drinking liquids, made sure I urinated at home before leaving, and excelled at locating unoccupied or single-occupancy public bathrooms.

When I was unable to urinate after a very long period of time, I resorted to catheterization – a process in which a sterile tube is temporarily inserted into the opening of the urethra to allow urine to flow out automatically. Medical personnel or friends performed this process for me until I learned to do it myself many years later. Catheterization was the only sure-fire method of which I was aware for finding immediate relief.

As the years wore on, my coping strategies began to expire. My bladder capacity, for example, diminished over time, and I could no longer hold my urine for excessive hours without feeling pain. Even after a successful catheterization, I often could not relax my bladder muscles enough to urinate on my own, sometimes for periods of up to three days.

### ***My constricted life: Why me?***

My fears and steady stream of obsessive thoughts resulted in my daily life becoming severely restricted. I constructed it around the presence or absence of bathroom facilities – and the people I might encounter in them. I missed out on all kinds of activities and opportunities: sleepovers, proms, sharing a ski cabin, backpacking in the wilds, any lengthy social or business engagement, travel, and many, many more. When asked to produce a urine specimen for a medical examination, I failed every time. In short, I felt paralyzed.

Even though I told my family and some friends about my distress, I felt alone and misunderstood, embarrassed and hopeless. The serious emotional toll that was exacted was just as debilitating as the physical discomfort. My self-esteem and self-confidence were eroded.

Gradually, over a period of time as my condition progressively worsened, I learned to avoid using public restrooms almost altogether and finally reached a point where I was afraid to leave my home with My Own Private Bathroom for more than a few hours at a time.

Why me? Why can't I be "*normal*?" What "*caused*" my problem, and how could I overcome it? As a researcher by profession, I felt compelled to find answers to my nagging questions. Over the course of many years, I consulted with a host of urologists, psychologists, psychiatrists, and social workers. I experimented with different kinds of techniques, such as biofeedback, meditation, hypnotherapy, gestalt, bioenergetics, acupuncture, visualizations, and the like.

No person or technique helped because the nature of my condition was misunderstood. Though well-intended, these health care professionals lacked the awareness that social anxiety disorders like mine respond well to one particular kind of short-term therapy called Cognitive-Behavioral.

## *A moment of tearful hope*

In 1997 I made a startling discovery that ultimately changed the course of my life. I located an Internet-based Discussion Forum (now operated by the International Paruresis Association or IPA ([www.paruresis.org](http://www.paruresis.org))). Here I found others with my symptoms, mostly men, who communicated and commiserated. I felt as if I had just found a lifeboat full of survivors from the same nightmare.

Tearful but overjoyed, I readily absorbed some basic information about my disorder and its effect on others. I learned that my condition:

- o Actually has a medical name – paruresis (par-you-ree-sis) – but is often more commonly referred to as “shy bladder” or “bashful bladder” syndrome. (Other names include “pee shyness” and the more technical term, “psychogenic urinary retention”).
- o Is considered a *performance*-based anxiety, or type of social anxiety condition, much like public speaking or the fear of eating or drinking in public. The person is usually, but not always, shy and fears being scrutinized or criticized by others when performing in public – in this case, urinating while in a restroom. The *Diagnostic and Statistical Manual of Mental Disorders IV* (DSM) categorizes paruresis as a social anxiety disorder, diagnostic code 300.23 (American Psychiatric Association, 1994).
- o Is one shared by many others – perhaps as many as 7% of the U.S. population (Soifer, 2001; Malouff, 1985). According to a sub-analysis of the 1997 National Co-Morbidity Study, 6.7% of a random sample of people in the United States said that they have difficulty urinating when away from home (Kessler, et al., 1998). Many of those are people with paruresis. Of those, a significant number are, like I was, critically impaired to the extent that their symptoms heavily interfere with their relationships, work, and travel.
- o Affects both men and women alike – but is more often recognized among men. Many of us are highly sensitive people who are intelligent, good, kind, and empathetic – people with qualities to be celebrated. We are simply bathroom-challenged individuals who have difficulty urinating under certain circumstances.
- o Is often kept a big secret by people who have it, usually out of shame and embarrassment.
- o Often goes unrecognized by well-meaning physicians and other health care practitioners who may be ignorant about its existence, resulting in faulty diagnoses and poor referrals.
- o Is the central focus of The International Paruresis Association (IPA) ([www.paruresis.org](http://www.paruresis.org)), a nonprofit organization whose mission it is to help paruretics (those with paruresis) overcome the stigma, embarrassment, and isolation associated with the condition. The IPA also sponsors workshops to

help sufferers overcome their condition and facilitates the establishment of support or self-help groups around the world.

### ***And the best news is that this disorder...***

is treatable with a variety of approaches, including psychotherapy, medication, and support group work, or a combination thereof. No one treatment is effective for everyone.

One highly effective approach has been through exposure-based Cognitive-Behavioral Therapy (CBT), a process that allows a slow and gradual recovery – like climbing the rungs of a ladder one step at a time.

- o The **cognitive** part helps identify and then alter distorted thoughts and attitudes regarding bathrooms and the people in them. For example, “People will think I am weird if I am sitting in a stall and they do not hear me urinate.”
- o The **behavioral** component utilizes the practice of desensitization techniques through which you learn to gradually expose yourself to (rather than *avoid*) increasingly difficult situations in which you find it difficult to urinate.

Chapter 9 covers CBT in greater depth.

### ***My journey toward recovery***

Simply put, I wanted my life back, and I was willing to tolerate all of the anxiety it took to reclaim it.

Supported by members and leaders of the IPA, both men and women, I began a journey toward a goal of complete recovery from paruresis, a passage that is a privilege to share with you.

It was clear to me that there was no “quick fix,” no “cure,” nor any pill or herbal supplement I could swallow to magically eliminate my symptoms. Rather, I knew I had to totally commit to a treatment program that would help me overcome paruresis.

I wasn’t quite psychologically ready to enroll in recovery workshops that were being offered by the IPA. Other events intervened that caused me great anxiety, sleepless nights, and panic attacks – a lumpectomy, pressure at work, and a crisis in my personal life. Very depressed, depleted, and at a low point, I consulted with a psychiatrist who prescribed Prozac™, an antidepressant, to stabilize my mood. Though highly resistant to taking it because of the stigma attached, I did because I had little choice. The psychiatrist also offered me something equally important – *hope*.

Six weeks later, the black clouds started to dissipate as the medication took effect. Many of my obsessive thoughts about urinating or not urinating faded. In a more relaxed state, I was able to cultivate a ho-hum attitude: “It’s fine if I urinate; fine if I don’t. I will not be concerned about the outcome.”

I went on to enroll in two IPA workshops, at which I made tremendous progress, step by step. Some of the basic and valuable lessons I learned:

- o When it comes to urinating, there are no such things as “successes” or “failures” (the IPA calls them “misfires”). The success is in the practice, not the outcome.
- o In order to recover, I had to let myself experience firsthand the terrible anxiety that results from not urinating, feeling all those uncomfortable, distressing feelings and reactions. I had to reject avoidance and face my fears. Though counter-intuitive, I had to take the risk of deliberately *not* voiding while in a bathroom so I could learn to tolerate, and ultimately conquer, the anxiety.
- o I have the right – the entitlement – to stay in a stall for as long as I want or need. I count just as much as anyone else!
- o I will not concern myself with what anyone else might be thinking about me when I use a restroom. Besides, they are likely to be self-absorbed, and furthermore it doesn’t matter to them if I can or cannot urinate.
- o The path toward recovery is not straight and consists of taking “baby steps.” Some days I will make progress, other days not. I’m not having a relapse – just a more difficult day – and each time is just a new experience.
- o It is not a catastrophe if I cannot urinate, even though I may be experiencing frustration, discomfort, or even pain. Even in the worst case scenario, I have alternatives, such as self-catheterization or finding relief by seeking medical attention.

### ***Practice makes perfect***

Armed with new-found confidence and dedication, I continued to practice – over and over – many of the exercises I learned at the IPA workshop. I treated recovery work like a job, which is what you must do if you are truly going to recover. I practiced a lot, with and without friends and acquaintances, exposing myself to situations I never thought possible.

What was new this time was that a switch had been activated in my brain. I actually *looked forward* to my practice sessions. I kept repeating a self-taught mantra, “*I’m a free peer (that’s pee-er), and I will stake my ground here for as long as I need.*” I felt a sense of power in relation to the bathroom that I had lost long ago.

No, these practice sessions weren’t always fun, and, yes, sometimes they were stressful. But instead of avoiding bathrooms, I confronted them head on. I made a game out of it, one which I felt assured I could win. “*Just come and get me, world; here I am!*” became my attitude.

Little by little, I started to feel – for lack of a better word – *normal!* I wasn’t consciously thinking of urinating. I assumed I would go and built on each success.

Through extensive communication with other female paruretics over the years, I also gained new insights about issues and behaviors that are unique to women. It is their highly personal revelations that, while anecdotal, have resulted in a cumulative knowledge base that forms the foundation of this book, and they're the people to whom I am especially indebted.

### ***Coming out of the (water) closet in other areas of my life***

As a result of my recovery, my life has changed in many remarkable and unforeseen ways. By completely coming out of the (water) closet, I have flourished in other areas of my life as well. (Note: For readers who may not be familiar with the term, "water closet" is a British term for toilet – as is "WC" and "loo.")

By feeling entitled to stay in a bathroom stall for as long as I like, I felt empowered – that I counted, that I was just as important as the next person. I took new risks: I got married for the first time! I became a step-grandmother! I became a much stronger person, able to face new challenges that I had formerly avoided.

Am I fully "*cured*"? No, but I have recovered to the extent that paruresis no longer controls my life. Sure, I experience hesitancy and an occasional "misfire" in certain situations, such as urinating outdoors, but probably no more so than anyone else. I no longer obsess about bathrooms, but I still carry my catheter kit with me just in case I need to get out of a difficult spot – only now it's buried at the bottom of my purse.

When I look back on my life's accomplishments, overcoming paruresis is definitely at the top of my list.

You, too, can leave the prison of Your Own Private Bathroom. You can be liberated! Let me show you how.

I wish you the best of luck.

P.S. For a more in-depth version of my personal journey toward recovery, turn to Appendix 3.