



Richard Daggett

## Neurogenic Bladder What Are My Options?

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If you've ever attended a post-polio support group, or participated in a conversation with another polio survivor, you might hear this question: "Do you think my pain is related to polio?" The answer: "It might be related, but it might not be related."

In recent months I asked myself a similar question, and gave myself a similar answer. But, since I am incurably inquisitive, I decided to try to find a more satisfying answer to the question, "Could this be polio related?"

I had a severe case of bulbospinal polio at age 13 in 1953 and was in a tank respirator (iron lung) for about six months. Although I had a moderate recovery, I was still visibly disabled – impaired pulmonary capacity and walked with a noticeable limp. And, as with many of us, I've had my share of post-polio issues.

About a year ago I began feeling that something wasn't right. For more than a month I had mild nausea, bloating and general malaise. I just didn't feel well. My primary doctor was on vacation, so in desperation I went to a local emergency unit. I must have looked dreadful because they saw me right away.

After an exam and an abdominal X-ray, the doctor came in to my cubicle and said, "You look like you are seven months pregnant." He wasn't smiling. It turns out I was retaining urine – three liters of urine!

It must have been building up over time. I had no pain and I thought I was urinating well – at least as well as any man my age. I was given a Foley catheter and I made an appointment with my urologist for the next day. The urologist said we should wait a couple of weeks, with the catheter in place, and then he would do some tests.

When I returned, he did a cystoscopy and a complete urodynamic study. This was uncomfortable, but not very

painful. He said the tests indicated I had a neurogenic bladder. I learned that a neurogenic bladder is a dysfunction that results from interference with the normal nerve pathways associated with urination. Hmm. Normal nerve pathways? Polio?

When I asked my urologist if this condition could have anything to do with polio, he said he doubted it, but seemed open to the idea. Most polio-related medical literature describes polio as a disease of the motor nerves. But having had bulbar polio, I know that polio damage can include more than just skeletal muscles. I began a serious search of available medical literature to see if I had missed something in my previous studies.

As I was searching I learned that a good friend had also been diagnosed with this condition and also had to have a Foley catheter. We are about the same age, and both of us had bulbospinal polio. And, in the past few months, I have heard of others with varying degrees of neurogenic bladder. Talking to these polio survivors re-awakened memories of my polio onset. I remembered being catheterized at the same time I was put in the tank in 1953. I remember telling the doctor I didn't need a catheter, and he replied, "You might need one pretty soon, and I'd rather we do this before you need it." These memories encouraged me to continue my research.

I found several references to neurogenic bladder on the Internet, and some of these mentioned polio. Almost all of these sites said something similar to: A neurogenic bladder is the result of

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interrupted bladder stimulation at the level of the sacral nerves. This may result from certain types of surgery on the spinal cord, sacral spinal tumors, or congenital defects. It also may be a complication of various diseases, such as syphilis, diabetes mellitus or poliomyelitis.

This was a partial help, but none of these references pointed to any reasons for polio to impact the bladder muscles. The only two published medical articles I could find were references in the *Journal of the American Medical Association* in 1948 and the *Journal of Urology* in 1936.

Regardless of the cause, the next question for me was what were my treatment options? The obvious first step was the indwelling, or Foley, catheter placed while I was in the ER. This eliminated the urine retention. This also brought almost instantaneous relief from my nausea and malaise. After I stabilized and all the tests were completed, my urologist suggested intermittent catheterization. This procedure requires that a person insert a disposable catheter several times a day. Because of my limited arm and hand strength this was very difficult for me. It was also fairly uncomfortable.

I have been using a Foley catheter, replaced monthly, for about one year.

It is not recommended to use one beyond that length of time because of the risk of infection, erosion of urethral tissue and other complications. If my urethral Foley catheter needs to be discontinued, a relatively common solution is to have a suprapubic catheter. This is an out-patient procedure to place a catheter into the bladder through a small incision in the lower belly. My friend with the neurogenic bladder has had a suprapubic catheter for several months and has had no problems. It is much more comfortable than the urethral catheter.

Another possible treatment is a “pacemaker” for the bladder. The one I have researched is the Medtronic InterStim®, used to treat incontinence and also retention problems. This small apparatus uses wires surgically implanted in the sacral nerves to stimulate the bladder muscles. Based on my research, I am not inclined to have such a surgical procedure at this time.

Decision time is rapidly approaching, and I will make my decision in consultation with my urologist. I welcome feedback from other polio survivors, and will post a medical update in a future issue of *Post-Polio Health*. ■

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## Jacquelin Perry, MD, 1918-2013

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When polio survivors in the 1980s began to experience symptoms of extreme fatigue, muscle weakness, joint pain and breathing difficulties, Dr. Perry was one of the first – along with PHI founder Gini Laurie and Dr. Lauro Halstead – to identify the condition as the late effects of polio.

She told the *New York Times* in 1985 that polio survivors “just push themselves more than most of us. They’ve put up with signs of strain to live a normal life. I always say people who had polio are overachievers, because so many of them are out to prove they can do just as well as those who didn’t have it. But now the strain has accumulated, and tissues are aging prematurely.”

Dr. Perry’s advice: “Modify your lifestyle to accommodate your new reality,” and “Listen to your body and adopt a program that avoids the strain.” ■