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 a question similar to this: “Do you think my pain is related to polio?” The answer is, “It might be related, but it might not be related. Just because you have had polio does not make you immune to other ailments.”

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

I had a severe case of bulbospinal polio at thirteen, 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 walking 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 and I was having difficulty making an appointment with a substitute. 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 to my urologist’s office, 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. Hmmm. 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. He 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 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 outpatient procedure to place a catheter into your bladder through a small incision in your 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 Interstim. This small apparatus uses wires implanted in the sacral nerves to stimulate the bladder muscles. Most Interstim implants have been used for incontinence. The medical literature also mentions its use for retentions problems, but this is much less common. The success rate for the Interstim when used for retention problems is only about 60 percent. I am not inclined to have another surgical procedure for this limited success rate.

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.