

# A Cautionary Tale about Post-Polio Shoulder Surgery: One Story, Three Perspectives

By Sunny Roller, M.A. and Frederick M. Maynard, M.D.

One must be very careful about choosing to have orthopedic shoulder surgery, especially if one is a polio survivor with a complicated disability. It's not because of the surgery itself. It's the complexity of the rehabilitation process and the uncertainty of functional outcomes that make it perilous.



*Liina Paasuke (left) connects over coffee with former colleague, Frederick M. Maynard, MD.*

A few months ago, we met with longtime friend, Liina Paasuke, over a lingering cup of coffee for a heart-to-heart conversation about her recent ordeal with shoulder surgery. Liina graciously told us her story that day. We asked her questions, listened, and took notes. Then the three of us shared ideas about how to proceed.

Since that empathetic and thoughtful exchange, we have individually continued to reflect upon Liina's difficult experience and have each come to evaluate the situation from our varied perspectives as the post-polio:

- medical specialist
- surgical patient and
- friend/consumer

In further conversation, we also resolutely agreed that Liina's story must be published.

To provide the narrative framework, we first present biographical background information about Liina, followed by the account of her surgical experience. Dr. Frederick Maynard then reflects upon what happened from his perspective as a post-polio physician. He offers important medical information and insights. Liina then provides a personal update as she continues her rehabilitation process. Finally, Sunny Roller reflects upon the whole experience as a friend with a similar post-polio disability who, like others, may someday face the same decision--whether to have such surgery—or not.

Due to little previous discussion of, or experience with this matter, a decision about having shoulder replacement surgery can suddenly confront and confuse people who are growing older with polio or other neuromuscular disability. It is our hope that by presenting Liina's account and our individual perspectives of it, readers--both consumers and professionals-- will more fully understand the issues and benefits of the choice to have, or to prescribe, shoulder replacement surgery (also known as Total Shoulder Arthroplasty or TSA).

### **Liina's Story**

Liina was born in 1948 in a German displaced persons' camp. She developed paralytic polio at age 17 months as she and her Estonian parents were arriving in Michigan after an immigration journey to the US. She spent most of the next four years in a Grand Rapids, Michigan hospital and underwent several surgical procedures on her severely paralyzed legs. By age six, when she began mainstream schooling, she was able to walk only by using bilateral long leg braces, a corset and bilateral forearm crutches.

After high school graduation, she studied at the University of Michigan and earned a Master's degree in Guidance & Counseling. She had a 36-year career with the Michigan Department of Vocational Rehabilitation at the University of Michigan, mostly providing counseling for people with physical disabilities. During her college and early employment years, Liina was entirely independent in all personal and advanced activities of daily living (ADLs). She walked as far as she needed or wanted to go using her devices with minimal difficulty. She drove a regular car with hand controls. In 1979, she purchased a 3-bedroom home that she still lives in today.

Although Liina's general health remained excellent, by the early 1980s she found it increasingly difficult to walk long distances and experienced symptoms of Carpal Tunnel Syndrome. In 1984, she obtained her first motorized scooter, had a ramp built for entry into her home and purchased a van with a rear swing-arm lift for scooter transport.

Over the next 20 years until her retirement in 2006, she very slowly gained about 25 pounds and gradually decreased the amount of time and distance that she walked due to increased effort and greater fatigue. By 2006, she was essentially ambulatory inside her home only. She began dragging her right foot during swing and could not negotiate a single step. By 2010 due to slowly declining strength and endurance, she could no longer complete bathing and toileting in a regular bathroom. Voluntarily, her longtime church's congregation immediately raised money to partner with Liina and a home improvement contractor. Together, after Liina tapped into personal funds and the church garnered additional financial support, volunteers got to work to complete the necessary architectural modifications. Within a few months, they had fully redesigned and remodeled Liina's home bathroom, bedroom and kitchen for fulltime scooter use. This collaboration with an exemplary church enabled her to remain independent in self-care and homemaking, primarily from her seated position.

Beginning gradually in 2012, she developed increasing right shoulder pain, especially with overhead elevation and turning. After her physiatrist diagnosed her with rotator cuff tendonitis, she had some short-term benefit from several bouts of Physical Therapy (PT) over the next three years. Nevertheless, she lost Range of Motion (ROM) and strength in the right shoulder. Her pain levels rose and severe pain was more frequent.

### *Her Choice to Have Surgery*

By late 2015, Liina decided to investigate surgical options for her right shoulder problems because of concerns that further worsening would jeopardize her ability to continue to live independently. Her primary goals were to maintain the ability to walk a little in her home, to stand up after toileting and to reach higher objects in her home. Her secondary goals were to decrease pain and increase ROM in the right shoulder.

She first saw a well-respected local orthopedic surgeon in the Ann Arbor, Michigan area. He referred her to another orthopedic surgeon who specialized in upper limb joint replacements and who performed “Reverse Total Shoulder Arthroplasty”(rTSA). In this procedure, the head of the humerus is removed and replaced by a shallow cup that articulates with a rounded ball (head) which is implanted firmly into the glenoid fossa of the scapular bone. This newer procedure is thought to restore better motion and strength in people whose shoulder rotator cuff muscles or tendons are torn or completely frayed from degeneration and cannot be repaired.

The surgeon led her to believe that the use of her arm would be as good as before. However, she was unable to have him answer specific questions regarding the eventual post-operative function of the arm for routine weight bearing which was critical for standing up and for transfers. The doctor said that the right shoulder would need to remain immobilized and bound to her chest for 6 weeks and thereafter she could gradually do anything she wanted to do and was capable of doing with that shoulder.

Despite reservations, she decided to proceed with the surgery. To prepare, she arranged to stay in a ‘subacute rehabilitation bed’ at a rehabilitation center with a good reputation in her community. She also quickly purchased an adapted minivan with a side ramp that would allow seated entry using her scooter. The **r-TSA** was done on April 13, 2016 and three days later, she was discharged to the rehab center.

### *Rehabilitation after Surgery*

She was dependent in all ADLs while her right arm was immobilized. She received therapy services and gained some modified independence in self-care using her non-dominant left upper arm and shoulder.

After four weeks, facility managers reported that they would very soon discharge her to go home alone because there were no further goals to meet *Medicare criteria* for her continued stay until she could

use the right arm again. She knew she would be unable to function at home alone. Appealing this decision based on her pre-existing condition of post-polio paraplegia was unsuccessful, but the facility did eventually allow her to stay longer after a follow-up visit with her surgeon. He gave her permission to begin some controlled motion exercises with the shoulder and to use the right upper limb below the elbow for ADLs.

After a nine-week stay, the rehab facility discharged Liina to go home. She could now perform basic ADLs from her scooter with great difficulty-- involving much time, effort and ingenuity. She received home therapy services for three months and increased the strength and ROM of the right shoulder. By five months post-surgery she was able to do all of her basic self-care independently with only mild to moderate additional effort and modifications than before surgery. She still could not stand up again after normal seated bathroom toileting, which limited her community re-entry.

Her right shoulder ROM was very good and she had no significant shoulder pain. When she began outpatient PT, her therapist noted surprising strength deficiencies in her shoulder's scapular stabilizing muscles, which he determined had not been specifically targeted for strengthening during her home PT exercises. He began targeted strengthening exercises for the right scapular stabilizing muscles and advanced her generalized upper body-strengthening program in order to assist her reach the goals of standing independently after seated toileting and for reaching high objects from standing.

At seven months post-surgery, she felt ambivalent about whether the surgery had been "worth it", but she was more hopeful about the chances of reaching her primary goals. She remained quite taken aback by how long her recovery was taking. Looking back, she felt that her surgeon had misled, even betrayed her, with false expectations, conflicting messages and unresponsive communication. Before the surgery, he said that recovery would be easy. She soon recognized his lack of knowledge concerning the polio survivor's potential challenges post-surgery. Since early on, he had ignored her questions. Her frustration grew when he would not return her emails and phone calls. He stated he had successfully operated on two other post-polio patients, but would not provide clearance for her to talk with them about their experiences. She continued to have some negative feelings about both his insensitivity and what seemed to be an unprofessional disregard for her physical condition. At this point in her recovery, she worried more than ever about staying financially and physically independent.

### **Frederick M. Maynard, M.D.—The Post-Polio Physician's Perspective**

#### *Identification of Surgical Goals*

One important lesson from Liina's story is how essential it is for people with chronic lower limb motor disabilities to identify their goals for having any shoulder surgery. This is particularly true for any functional goals that have been lost and are hoped to be regained, or for functional goals critical for independence that are in jeopardy of being lost. While pain reduction and improved ROM may be desired, and are considered likely to be obtained from a successful surgical procedure, the

achievement of any eventual post-operative goals dependent on higher levels of upper limb strength are harder to predict. Due to many unpredictable intervening variables, their achievement may require prolonged challenging effort by both professionals and patient. Honest and frank discussion about this reality pre-operatively between surgeon and patient can mediate any disappointing results.

### *Accepting the Lack of Medical Knowledge*

A second lesson from Liina's story is greater awareness of how little the medical community knows or understands about the unique needs of people with chronic lower limb motor disabilities. This case in particular elucidates the current paucity of medical knowledge about successful post-operative restoration of weight-bearing function with the shoulders and upper limbs after a new reconstructive orthopedic procedure on the shoulder joint. Given the impressive results of TSAs for reducing pain and restoring functional ROM for otherwise able-bodied people, these procedures are likely to be offered to and considered by people with chronic lower limb motor disabilities more frequently in the next 10 years. This is a predictable result of first, the high frequency of shoulder pain problems observed among people with Spinal Cord Injury-related paraplegia (>80% incidence after 20 years post-injury). Second, it is inevitable that there will be greater need for TSA in the burgeoning older age cohort of people living with conditions such as post-polio, spina bifida, cerebral palsy, muscular dystrophy and other neuromuscular conditions who routinely use their upper limbs to bear full body weight. A medical literature review identified only two reports that addressed outcomes of TSA among a few people with paraplegia (including two patients with polio).<sup>1 2</sup> Medical and surgical complications were numerous and functional outcomes beyond pain reduction and ROM were not well described. Just as hip and knee joint replacement surgery has become commonplace in the USA for treating older age-related "wearing out" dysfunction of these joints, shoulder joint replacement is becoming more widely and readily available. Many efforts at new and improved designs of utilized hardware and for surgical tactics are likely; but specific study, or even note, of the special needs, problems or complications of people with chronic lower limb disabilities having these procedures seems unlikely.

### *Current Recommendations*

Not enough is known about post-surgical functional outcomes in people who regularly need to use both shoulders to support their full body weight. Consequently, for the present, I recommend great caution when considering TSA or rTSA. Clear goal identification for having any procedure, excellent communication between patient and surgeon about goals and special needs, and consideration of second opinions are also recommended. I am also promoting to my surgical and rehabilitation

---

<sup>1</sup> Hattrup SJ, Cofield RH. Shoulder arthroplasty in the paraplegic patient. J Shoulder Elbow Surg 2010; 19 : 433-438.

<sup>2</sup> Garreau De Loubresse C, Norton MR, Piriou P, Walch G. Replacement arthroplasty in the weight-bearing shoulder of paraplegic patients. J Shoulder Elbow Surg 2004; 13 : 369-372.

colleagues further investigation of strength and functional outcomes achieved after these procedures among people who rely on body weight bearing shoulder function.

### **Liina Paasuke—The Post-Polio Surgical Patient’s Perspective**

#### *Post-Surgery Shockers*

Now, nine months after her surgery, Liina reports that she is slowly regaining her strength and function, but is still not back to her pre-surgery capabilities. Astonished by the potent consequence of short-term muscle disuse for polio survivors, she has been dismayed by several post-surgery shockers. First, her total upper body strength is diminished, on both the right and the left sides. Second, crutch walking is now grueling and, right after the operation, she could not even move her right leg to take a step, as she was used to doing before the surgery.

Third, Liina is functionally able to do a greater number of activities than she could right after her surgery, but she has also needed a greater number of environmental supports, which have been very expensive. She has purchased an adapted minivan and paid a contractor to construct a new door built into the sidewall of her one-car garage for entering and exiting her car, using the side ramp. She also bought an electric bed that raises, lowers, and has bedrails. She had more functional grab bars installed in her bathroom and bought a seat height extender for her scooter. She has newly hired a physical therapy assistant who helps her at home with exercises and some tasks around the house at \$15.00/hour, which is a reasonable rate. Liina discloses that all of these new adaptations at home have “eaten away at my confidence for any future travel that would involve staying overnight in hotels, condos and friends’ homes.”

#### *Lessons Learned*

Liina shares that she has learned firsthand how debilitated a polio survivor can become after just two months of inactivity. She was led to believe she would have a short recovery time. But even nine months after surgery, an all-encompassing sense of exhaustion when doing previously-normal activities has been overwhelming. As she now works to train her right shoulder muscles to compensate and operate in different ways than before, she cautions post-polio consumers to “carefully weigh any surgeon’s expectation against reality”.

She also recommends that the post-polio patient learn everything possible about Medicare payment guidelines. Scared that she would either be forced to go home alone before she could function, or have to pay out of pocket the daily cost of her nursing home rehab stay, she thanks Post-Polio Health International (PHI) for sending information about Medicare’s rehabilitation improvement standards. See article titled, “Judge Orders Medicare Agency to Comply with Settlement in ‘Improvement Standard’ Case, Provide More Education” at [www.medicareadvocacy.org/medicare-info/improvement-standard](http://www.medicareadvocacy.org/medicare-info/improvement-standard).

After sharing this article with the Rehab Center, they got around it somehow, but she felt that at least it was self-empowering to wave it at them. She also warns not to trust the knowledge that an inexperienced social worker may have. Hers was not helpful at all. She also had a home physical therapist early on who was not helpful due to lack of post-polio knowledge. Often left to advocate for herself from her weakened position, Liina confides, “It’s tough to fight when you’re down”. So, the advice is--prepare. Find a strong, enduring personal advocate before surgery and go into surgery armed with a list of resources such as senior centers, The Area Agency on Aging, Medicare, other insurance company numbers, PHI, local polio networks and support groups.

Liina has been home for seven months now and is doing regular physical therapy at home and at a special supervised physical therapy gym program. She has re-joined WeightWatchers to lose a little weight. She reports that the pain in her right shoulder is indeed gone and she moves it much more easily. She also reports that this experience has certainly been enlightening, but she would definitely think twice about having the same surgery in her left shoulder, which her surgeon recommended, if it further deteriorated. She is still not back to her desired level of functioning yet but is hopeful about making new gains. Liina says her story of surgery is definitely still a journey in progress. Maybe she’ll know if it was worth it in two years...or so.

### **Sunny Roller—The Post-Polio Friend and Consumer’s Perspective**

As a polio survivor who grew up walking with crutches and braces and now at the age of 69 uses a scooter full time, I am very grateful to Liina for having the courage to reveal her private story to the rest of us. Even from the sidelines, hers has been a fear-provoking experience for me to witness and imagine. In the past, I had had firsthand experiences with broken legs that had taken nine months to heal and involved extensive rehab—and that was when I was much younger. What would happen with major surgery at this stage in life? At times, I was so worried for her. But I have also been impressed with her hutzpah. From my perspective, she took a huge medical risk. She chose to venture down the proverbial “road less traveled” not knowing what to expect; and it has indeed been a somewhat darkened and physically dangerous forest filled with ignorance and falsehoods to battle. But Liina is steadfast. She has been resolute about getting through this ordeal. She has been tapping in to her ingenuity and sense of hope all along the way, and is closer to her goal of continued independence with a shoulder that doesn’t hurt.

#### *My Take-Away Lessons*

Liina has shared her arduous ordeal so we may better prepare for any future major surgery that might be prescribed for us. After being close enough to witness and empathize with Liina’s experience, here are my take-away lessons:

- We all have much more to learn about this type of surgery for polio survivors

- If surgery is prescribed, always get a second or third opinion from a non-surgeon post-polio specialist
- If you have a bad feeling about the surgeon and his office staff, trust it. Find someone else
- Research all the alternatives to having this type of surgery. Consider thoroughly the future impact of any risks if you decide to opt out of this surgery
- Know that muscle disuse in a polio survivor zaps previously accustomed strength and the ability to function and this is inevitable in any immobilized post-operative limb. Assume that the post-surgical rehabilitation will take much, much longer than anyone expects; then plan accordingly
- Prepare thoroughly before the surgery. This includes:
  - Making sure the surgeon's team is informed about the proper cautions for anesthesia and recommended surgical recovery room procedures for polio survivors
  - Finding, even touring and interviewing at the best place for your rehabilitation based on location, skill, reputation, knowledge of polio survivor issues
  - Recruiting a loyal personal/professional patient advocate who will persevere and stand up for you through the whole process--from start to the point of fullest recovery
  - Tapping into your network of family and friends in advance for possible pledges of assistance; asking them to help mainly with what they are good at and like to do ("it takes a village!")
  - Gathering all information possible about resources that might be needed
  - Talking to occupational therapists in advance about home rehabilitation, care and recovery needs including possible home modifications
  - Talking with physical therapists about alternate ways to transfer and move about during post-surgery rehabilitation
  - Identifying post-polio specialists who will agree to consult with health care professionals about specific post-polio issues. PHI is a great resource for this information
  - As if going away on a trip, preparing your home indoors and out for your potentially lengthy absence
- After surgery and during the rehabilitation process, know that you and your advocate will need to teach most of your helping professionals about how best to care for you on a daily, even hourly basis
- Understand that recovery will not be easy, but it might be worth it. Weigh the pros and cons judiciously.

**This is indeed a cautionary tale.**