THE POLIO PERSPECTIVE

AUGUST, 2014

IN THIS ISSUE

PREVENTING COMPLICATIONS IN POLIO SURVIVORS UNDERGOING SURGERY or RECEIVING ANESTHESIA

Dr. Richard L. Bruno
Chairperson
International Post-Polio Task Force
and
Director
The Post-Polio Institute
International Centre for Post-Polio Education and Research
PostPolioInfo@aol.com

Long before surgery, you and your doctors need to read this:
Propofol is used at The Post-Polio Institute for anesthesia induction or brief procedures (e.g., colonoscopy).
Desflurane is used if gaseous anesthetic is needed and while brain waves are monitored.

Unfortunately, only a handful of specialists treat Post-Polio Sequelae (PPS) - the unexpected and often disabling fatigue, muscle weakness, joint pain, cold intolerance, and swallowing, sleep and breathing problems - occurring in America's 1.63 million polio survivors 40 years after their acute polio. However, all medical professionals need to be familiar with the neurological damage done by the original poliovirus infection that today causes unnecessary discomfort, excessive physical pain and occasionally serious complications after surgery. This is a brief overview to inform patients and professionals about the cause and prevention of complications in polio survivors undergoing surgery.

PRE-OPERATIVE PREPARATION

The pre-operative period is the most important, since it is when polio survivors must establish communication with the surgical team. After the second opinion and a polio survivor's decision to have surgery, the patient needs to ask the surgeon to read this article and the references cited. Then, surgical candidates must meet with the surgeon and anesthesiologist to discuss in detail patients' complete polio and general medical histories and the problems that will likely arise before and during surgery, in the recovery room and on the nursing floor. It is also recommended that the polio survivor meet with the Supervisor of Nursing on the floor where they will be transferred after surgery to discuss likely problems during the post-op and recovery period.

Lungs. We recommend that all polio survivors have pulmonary function studies as part of their pre-operative testing.This is vital for those who had bulbar polio acutely, whether or not they used a respirator or an iron lung. But, polio survivors who have (or had) neck, arm or chest muscle weakness or have swallowing problems should also have their lung function tested so there will be no unpleasant surprises coming off the respirator at the end of the operation. Polio survivors with a lung capacity below 70% may need a respirator or respiratory therapy after surgery. Of course, polio survivors who use a respirator during the day or at night must discuss their respirator use and maintenance in detail with their surgeon, anesthesiologist, the nursing staff, and with their own pulmonologist, before admission to the hospital.

Physical Assistance. X-rays are a normal part of pre-op testing. Because of workers

compensation concerns, many hospital staff are not eager to move or lift patients. Unfortunately, X-ray and examining tables are built at heights that are convenient for the professional, not the patient. Many polio survivors cannot step on a stool to get onto a high table, or even pull themselves over onto a table from a stretcher. Thus, polio survivors must ask for help in transferring.

Since most polio survivors have no experience asking for help under any circumstances, they need to find a phrase with which they are comfortable that will communicate whatever their needs are. Long explanations about having had polio or PPS or the specifics of which muscles are weak or paralyzed are not necessary. For example, a simple "My legs (arms) are paralyzed and I can't get onto that table; I will need help" should suffice. This phrase may have to be repeated before the polio survivor will be assisted.

If the professional replies, "Oh, I bet you can move by yourself if you try!" or "Don't expect me to lift you," an appropriate response is "I cannot get onto the table. Please ask someone else to help me or let me speak to your supervisor." A pleasant but steadfast refusal to do difficult or dangerous transfers is the polio survivor's best defense against injury before or after surgery.

General Anesthetics. Polio survivors are exquisitely sensitive to anesthetic. It has been known for 50 years that the poliovirus damaged the area of the brain stem - called the reticular activating system (RAS) - responsible for keeping the brain awake. Because the RAS was damaged in those who had paralytic and non-paralytic polio, a little anesthetic goes a long way and lasts a long time.

For example, the pre-operative medication used to "calm" surgical patients - sometimes Valium or Vistaril - may by itself put polio survivors to sleep for 8 hours. (Such excessive and prolonged sedation does occur when low-dose Propofol is used alone in patients undergoing invasive but nonsurgical procedures, like endoscopy.) Add to a pre-operative "calming cocktail" an intravenous anesthetic (like sodium pentothol) or a gaseous anesthetic, and polio survivors have been known to sleep for days. Again, Propofol is the drug of choice for polio survivors.

In addition, polio survivors with respiratory problems may have trouble clearing the gaseous anesthetics. A number of our patients have awakened from anesthetic on a respirator in I.C.U. to the frightened faces of their family, surgeon and anesthesiologist several days after surgery.

Here is the first of rule of thumb - we call "Rules of 2" - for polio survivors having surgery:
ANESTHETIC RULE OF 2:
Polio survivors need the typical dose of anesthetic divided by 2.

This first "Rule of 2" is certainly NOT intended to dictate the dose of anesthetic, but merely to remind anesthesiologists that polio survivors need much less anesthetic than do other patients. This does not mean that a given polio survivor might require less than 1/2 the typical anesthetic dose, or that another won't need more anesthetic. As always, the dose of

anesthetic must be individually adjusted (for body weight, lipid space, etc) and be adequate to keep patients under during surgery but not cause them to sleep for a week. We have found Desflurane to be the best tolerated anesthetic when used with brain-wave monitoring.

Even applying the "Anesthetic Rule of 2" polio survivors may be very sedated, if not asleep, for many hours after the surgery. This is one of the reasons why same-day surgery -even for complicated dental procedures - is not advisable for polio survivors. Sleeping or excessively sedated polio survivors cannot be expected to return home and take care of themselves after same-day surgery, since surgical complications may go unnoticed and sedation-impaired coordination makes falling likely.
In spite of HMO pressure, *NO POLIO SURVIVOR SHOULD HAVE SAME-DAY SURGERY* except for the most simple procedures that require only a local anesthetic.

Nerve Blocks. However, there are also problems with local anesthetics that numb only one area of the body. Spinal anesthetics, like epidural or saddle blocks used for childbirth and lower body procedures, often allow surgery without the patient being asleep and are therefore more desirable for polio survivors. However, the injection of a local anesthetic near the spine results in both pain-conducting nerves and motor neurons being anesthetized. Polio survivors are very sensitive to anything that further impairs their polio virus damaged motor neurons and a spinal anesthetic may cause polio survivors to be paralyzed for many hours. If a spinal anesthetic is used, polio survivors cannot be expected to get up and walk after surgery.

Curare-like drugs that are intended to paralyze muscles (e.g., succinylcholine) are typically used during major surgery to relax muscles that are going to be cut and make it easier for the ventilator to fill the lungs while patients are on the table. Again, any drug that interferes with muscle functioning will prevent polio survivors from walking or even moving for hours longer than it would for patients who didn't have polio.

Regardless of whether a local, spinal or general anesthetic is used, the following applies:
POST-ANESTHETIC RULE OF 2 :
Polio survivors require 2 times as long to recover from the effects of any anesthetics.

Blood and Guts. There are yet additional concerns. Polio survivors with muscle atrophy, especially in the thigh muscles, will have a smaller blood volume than would be expected for their height or weight. Therefore, bleeding during surgery may be more of a problem. Polio survivors may want to bank their own blood slowly over the course of weeks, even for procedures where excessive blood loss is not typically expected. However, since polio survivors may be significantly more fatigued and prone to faint after giving blood, relative's blood may need to be banked instead.

Also, polio survivors can be sensitive to atropine-like drugs used to dry secretions during surgery. Atropine-like drugs also slow the gut, and polio survivors may be excessively constipated after surgery or, rarely, actually have their intestines stop moving (paralytic

ileus) for a period of time. These problems can be treated symptomatically as they would in someone who did not have polio.

Positioning. One overlooked problem is the positioning of the post-polio patient on the operating table. Muscle atrophy, scoliosis and spinal fusions may make certain positions problematic, especially those involving extension of the spine. Since the polio survivor is usually unconscious during positioning, there will be no report of pain that would normally warn of potential damage. A number of polio survivors have experienced severe back pain for months post-op, and even permanent traction injuries of nerves, after being placed for hours in damaging positions. It would be advisable for the patient to be awake during positioning on the table to prevent such post-op complications.

POST-OPERATIVE CARE

Cold. If the dose of anesthetic is carefully regulated, a polio survivor's first post-op experience will be waking in the recovery room. Often, polio survivors awaken from anesthetic shivering violently. Research has shown that polio survivors are extremely sensitive to cold because they have difficulty regulating their body temperature. Polio survivors' automatic (autonomic) nervous systems were damage by the poliovirus from the brain (hypothalamus) through the brain stem (reticular formation and vagal nuclei) to the spinal cord (intermediolateral columns). Polio survivors cannot control the size of their blood vessels, since the nerves that make the smooth muscle around veins and capillaries contract were paralyzed by the poliovirus. Therefore, polio survivors' blood vessels open under anesthetic and dump the heat of their warm blood into the cold recovery room.

Recovery room nurses need to know about this problem and help polio survivors stay warm. Additional blankets will help, and the surgeon can even write an order for a heated water blanket to be used in recovery.

Vomiting. Another post-op problem related to brain stem damage is vomiting. As in anyone who receives a general anesthetic, polio survivors can develop nausea and vomit. However, polio survivors are more apt to faint (have vasovagal syncope and even brief asystoles) when they attempt to vomit. It is very important that post-operative emetic control be discussed with the anesthesiologist and administered before polio survivors go to the recovery room and that additional medication is written as needed in the post-op orders.

Choking. Yet another concern is difficulty swallowing as the patient is awakening. Polio survivors who are aware of having swallowing problems, and sometimes in those without apparent swallowing difficulty, cannot clear secretions and may choke (or feel like they are choking) when they are lying on their backs, still half asleep, as the anesthetic is clearing. Polio survivors' secretions need to be monitored in the recovery room and they should be positioned on their side if possible so that secretions can drain.

Pain. The single most troublesome problem after surgery is pain control. A number of studies have shown that many surgical patients are under medicated for pain. Under medication is a serious problem for the post-polio patient since two research studies have shown that polio survivors are twice as sensitive to pain as those who didn't have polio. Increased pain sensitivity is apparently related to poliovirus damage to endogenous

opiate-secreting cells in the brain (paraventricular hypothalamus and periaquiductal gray) and spinal cord (Lamina II of the dorsal cord).

RULE OF 2 for PAIN:
Polio survivors need 2 times the dose of pain medication for 2 times as long. Since polio survivors are known to be extremely stoic, they are not likely to abuse or become dependent upon narcotics.

RECOVERY

In keeping with the "get 'em up, move 'em out" trend in medicine, there will be the tendency to get polio survivors up and walking almost immediately after surgery. This is not advisable for a number of reasons. When polio survivors reach the nursing unit, they may still be twice as sedated from the anesthetic as are other patients. Since polio survivors need a very clear head to be able to control their weakened, polio-affected muscles to stand and walk, a fuzzyheaded polio survivor is at serious risk for falling.

Even if a polio survivor's head is clear, the anesthetic or other drugs may have temporarily weakened or even paralyzed the muscles needed to stand and walk. What's worse, the surgery may have cut muscles (especially abdominal muscles) that substitute for muscles paralyzed by polio (it is often muscle substitution that actually allows polio survivors to stand and walk, even though the muscles that are typically needed to walk were permanently paralyzed). Not only will post-polio patients be unable to stand or walk, they may also be unable to even move to position themselves in bed. Polio survivors may also have low blood pressure after surgery that could itself cause lightheadedness, fainting and falls.

RULE OF 2 for RECOVERY:
Polio survivors should stay in bed 2 times longer than other patients. Under any circumstances, polio survivors should get up slowly, first sitting up in bed, then sitting with feet dangling, then getting into a bedside chair with assistance, then standing with assistance and finally walking with assistance and appropriate assistive devices. With the necessity of additional bed rest, anti-embolism stockings to prevent blood clots may be a prudent precaution. Gentle physical therapy in bed may be advisable to maintain range of motion and for stretching, since polio survivors are prone to developing painful muscle spasms if they are not up and moving.

RULE OF 2 for LENGTH OF STAY

Polio survivors need to stay in the hospital 2 times longer than other patients. While polio survivors may become deconditioned with bed rest somewhat faster than others patients, because of autonomic nervous system damage, the dangers of getting them up and walking too quickly far outweigh those of moving too slowly. Polio survivors have learned to be very aware of what their bodies can and can't do. They are the best judges of when they can move, stand and walk safely.

Nursing Care and Nurse Caring. Polio survivors often have difficulty merely being in the hospital. They may have insomnia, anxiety, and even have panic attacks. These symptoms are easy to understand when it is remembered that as young children, polio survivors were ripped away from their families and admitted to rehabilitation hospitals for months or even years. Post-polio children underwent multiple surgeries and painful physical therapy, procedures administered often without explanation and certainly without their consent.

Many post-polio patients have had multiple experiences of psychological, physical and even sexual abuse at the hands of hospital staff. Questions or complaints about painful and frightening therapies were not infrequently met by staff anger or punishment. Patients report having been locked in dark closets overnight when they asked questions, spoke out or cried. Necessary nursing care could be withheld for no apparent reason. Many post-polio children were slapped and some were actually beaten with rubber truncheons by physical therapists to "motivate" them to stand up and walk.

It is not surprising that polio survivors can be terrified of again becoming powerless patients at the mercy of hospital staff. Nursing staff's appreciation of the childhood trauma polio survivors experienced at the hands of medical professionals, and taking a moment to actually listen and respond to the real needs of the adult post-polio patient, will go far toward making the patient feel safer and more comfortable during their stay.

Returning Home. There is another "Rule of 2" when surgical patients return home:
RULE OF 2 for WORK:
Polio survivors need 2 times the number of days of rest at home before they return to work or household duties. For all of the reasons described above, the entire recovery process takes longer for polio survivors. It is not uncommon for typically overachieving, hyperactive Type A polio survivors, who were taught as children to "use it or lose it," to return to work or household duties the day after they return home from the hospital.

Polio survivors must be encouraged to rest and to return to activities slowly, especially if they are somewhat deconditioned and feel weaker or more fatigued post-op. Polio survivors should ask their surgeon for a note that allows them to stay home from work twice as long as the typical patient.

Post-Op PPS? The 1985 National Survey of Polio Survivors has shown that emotional stress is the second most frequent cause of PPS (after physical overexertion). Certainly, there are few emotional or physical stressor more potent than surgery. So, polio survivors should expect some increase in fatigue and muscle weakness resulting from the combination of the physical and emotional effects of the surgery, anesthesia, other

medications, and bed rest.

However, only a handful of post-polio patients permanently lose function after surgery. strength or endurance lost after surgery are typically recovered. To aid recovery, gentle physical therapy may be advisable. Passive stretching, range of motion exercises and slowly increasing endurance are more valuable than muscle strengthening exercise which can actually cause muscle weakness. Especially if a polio-affected part of the body has been operated on (stomach, back, arms or legs), a physiatrist who is thoroughly knowledgeable and experienced about the care of polio survivors and PPS should be consulted before surgery so that a post-op rehabilitation plan can be in place. A short stay in a rehabilitation hospital after surgery (especially after back or leg surgery) may make polio survivors recovery safer, faster and more complete.

Polio survivors need to remember:
RULE OF 2 for FEELING BETTER:
Polio survivors need 2 times longer to feel "back to normal" again.

CONCLUSION

All of the "Rules of 2" are suggestions for polio survivors and the surgical team; they are not a substitute for specific information about the individual patient and communication among all members of the treatment team, including the patient. All polio survivors must be evaluated and managed according to their individual needs. Please take the time to read the following references (especially those in bold type) so that you will be fully knowledgeable about and be able to help meet polio survivors' special needs.

POLIO SURVIVORS' PRE-OP CHECKLIST

* Give articles to surgeon and discuss:
* Pre-op lung tests.
* Possibly having lower blood volume and blood banking or bloodless surgery?
* Authorization for a longer stay in the hospital.
* Orders for post-op anti-vomiting medication.
* Positioning on the table during surgery.
* Orders for staying warm in the recovery room.
* Difficulty clearing secretions in the recovery room and on the nursing unit.
* Orders for increased dose of pain medication.
* Physical therapy for stretching and range of motion in hospital.
* Placing articles about polio in the medical chart.
* Give articles to anesthesiologist and discuss:
* Any lung problems
* Lower dose of pre-op calming medication.
* Lower dose of anesthetic.
* Longer-term paralysis of muscles with spinal anesthetic and curare-like drugs.
* Orders for post-op anti-vomiting medication.
* Difficulty clearing secretions in the recovery room.
* Give articles to nursing supervisor and discuss:
* Longer-term sedation with anesthetic.

* Difficulty clearing secretions on the nursing unit.
* Orders for increased dose of pain medication.
* Needing help in moving in bed and in the room.
* Not standing or walking until you are fully awake and able.
* Anti-embolism stockings.
* Meet with PPS physiatrist before surgery and discuss:
* Post-op rehabilitation plan.
* Physical therapy for stretching and range of motion in hospital.
* Possible admission to a rehab hospital before going home.
* Physical therapy for walking and increasing endurance at home.

SITTING PRETTY

By Millie Malone

One of my friends brought up an interesting subject. Well, interesting to me and my female readers mostly, I suppose. The question is this: How do you keep your knees together while sitting in your wheelchair if you don't have the muscle strength to do so? Perhaps men would like to look less splayed out, too, but for us women it is a modesty issue.

In the summer, I wear skirts rather than pants because I am always too warm. As opposed to the winter, when I'm always too cold. I was taught that it wasn't lady like to cross one's legs, but you could cross your ankles. That always brought vividly to mind the leader of a girl's group I belonged to in my teens. Those rules were vigorously applied in this organization, so the girl leading our group never crossed her legs. However, when she crossed her ankles, her knees were defiantly pointed away from each other. You know how rebellious teenage girls can be and this was an era where that was considered very rebellious indeed.

So what is the answer? Some people suggested a belt applied to the legs either above or just below the knees. If you are in your chair all the time, that might work for you. I know I would totally forget my knees were tied together and would stand up and fall on my face. It would prevent my usual fall, though. The one where my left leg goes straight out in front of me and I land on my much abused "good" knee. That has happened so often that I've had to put quotes around the word "good."

Perhaps a dot of stick-on Velcro applied to the inseam of one's pants? Duct tape? Maybe a pillow tucked in beside your thigh to force your legs closer together? I can tuck my polio affected ankle behind the other one and that keeps my knees together, but I can only hold that position so long before my legs go to sleep. At this point in my life, I can still remember that the ankle is trapped behind my other ankle, but I'm getting older and I can foresee a day when I'll forget even that. There could be a face plant in my future.

In the winter, a blanket over your legs solves the problem nicely and kills two birds with one stone, something I'm always in favor of. If anyone has a good solution to this

problem, please let me know. For now, I will wear longer skirts in the summer. Not those beautiful gauzy full skirts I love so much, though. Nope. They get caught in my wheelchair's wheels and get torn off. When that happens, I have bigger problems than just keeping my knees together.

THROWBACK THURSDAY

David G. Oakley

(Editor's note: On Facebook, people write or display pictures of times past, hence the name Throwback Thursday. David Oakley impressed me with this piece and I thought you would also like it.)

Throw Back Thursday. July 2, 1958. It was a very hot, very sultry day, as only an Iowa summer day before A/C could be, on Golden Street. A street normally teeming with children at play, Golden Street was absent any of its normal activity. At one point I heard it coming from the North. Crossing the lawn between Tom and George's house and ours, I looked up to see a huge aircraft flying over. It appeared to be following the Bluegrass Creek, going South behind our home. It was flying so low I could see the men inside the cockpit. It got even hotter. There was not a breath of air. I sat on the back step and petted Shep for a while. Shep was tied up, as strays were being rounded up around town. I hated it that he was restrained that way. Shep was an amazing dog. During the school year he walked Tom, George, and I to school. According to Mom, he would come home and lie in the shade all day, and then he would leave just before school was dismissed to meet us at the door. I loved Shep. That day went from miserable to unbearable to deadly for too many, including Shep. We were evacuated in the late evening, not long before a 10 foot wall of water came rushing down far out of the banks of the Bluegrass Creek, slamming the rickety old house North of us into our home and sweeping it off its foundation and up against the trees along the South property line. We had gone to the home of friends 2 blocks West, high on a hill, to spend the night, and all night I was asking about Shep. I believe 19 people died the night of the 1958 flood. I was told Shep would probably come home in a few days. I would dream, nearly every night, that he was running to me. He would be coming down the hill from the golf course West of our home, rising and falling above the tall grass, his ears bobbing up and down, and I would awake to the new day's reality of his absence and the hole in my stomach would grow in size and intensity. Those days were so painful, yet so hopeful. For too many folks those days were absent hope, and just terribly sad, as they had lost loved ones in the flood waters. Our family survived but our lives were changed for ever. A few weeks after that terrible night, and after so many terribly painful mornings, my cousin Ervin innocently told me that Uncle Lloyd had buried Shep the day after the flood out behind where our house had been. Painfully blindsided by the reality of Shep's death I eventually began to heal. I was 11. Shep and I had only had about 3 years together. Yet looking back it seems like half a lifetime. I believe there is still a playground above where Shep lies.

Am I a Cripple?

Lavonne Schoneman

Some would think so
but I do not.
Why?
Why indeed!
My mind and emotions
are truly functioning.
It's true a wheelchair
is my mode of transportation.
I cannot walk anymore.
One hand and arm
do not function
as they once did
due to a stroke.
However, in spite of my
many disabilities
(Including post-polio)
I refuse to countenance
the idea that "I"
am crippled!
Why is this so?
An insuperable theory
is one which cannot
be overcome in some way
Any idea or suggestion
could cripple someone,
or not, depending upon
how it is received and
acted upon -- or not.
Better to keep focused on
what is still possible
within my realm.
Rather than dwell on what
cannot be done, I concentrate
on those things that can
and will give me pleasure!
Even a feeling of self-worth.
LaVonne Schoneman (c) 2014

WEB CORNER

Officials Declare Overseas Polio as Public Health Emergency

http://www.defense.gov/news/newsarticle.aspx?id=122747

Ken Burns Turns His Lens on Roosevelt Dynasty

http://news.msn.com/pop-culture/ken-burns-turns-his-lens-on-roosevelt-dynasty

Michigan Polio Network newsletter
http://www.michiganpolionetwork.com/chairman-s-comments
Avoid Patronizing Conversations With People With Disabilities
http://www.transfermaster.com/blog/view-post/Avoiding-Patronizing-Conversations-with-People-with-Disabilities
A Wonderful Device Set to Make Wheelchairs Obsolete
http://www.transfermaster.com/blog/view-post/A-Wonderful-Device-Set-to-Make-Wheelchairs-Obsolete
Wheelchair Accessible Treehouses
http://www.transfermaster.com/blog/view-post/Wheelchair-Accessible-Treehouses
Soaring on Your Wheels With the Firefly Attachment
http://www.transfermaster.com/blog/view-post/Soaring-on-Your-Wheels-with-the-Firefly-Wheelchair-Attachment
The Realities of Wheelchairs and Medicare
http://savemymedicalsupplies.org/realities-wheelchairs-medicare/
Not Until the 1950s Were Rehab Programs Available for Polio
http://www.cowichanvalleycitizen.com/living/not-until-the-1950s-were-rehab-programs-available-for-polio-1.1069238
Pathways that direct immune systems to turn on or off found
http://www.sciencedaily.com/releases/2014/03/140317124952.htm?utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A%20sciencedaily%20(Latest%20Science%20News%20--%20ScienceDaily)&utm_content=My%20MSN

A LITTLE BIT OF HUMOR

Hot Bath

Feeling edgy, a man took a hot bath. Just as he'd become comfortable, the front doorbell rang. The man got out of the tub, put on terry cloth slippers and a large towel, wrapped his head in a smaller towel, and went to the door. A salesman at the door wanted to know if he needed any magazines. Slamming the door, the man returned to the bath.

The doorbell rang again. On went the slippers and towels, and the man started for the door again. He took one step, slipped on a wet spot, fell, and hit his back against the hard porcelain of the tub.

Cursing under his breath, the man struggled into his street clothes and, with every move a stab of pain, drove to the doctor. After examining him, the doctor said, "You know, you've been lucky. Nothing is broken. But you need to relax. Why don't you go home and take a long hot bath?"