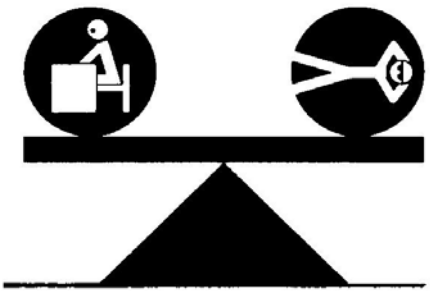
POST POLIO PACER



Conserving Strength and Energy through Pacing
October 2009 —– Madison, Wisconsin
Madison Area Post Polio Support Group Newsletter
MAPPSG formed in 1985

Emergency Care – Are You Ready?
By Mary Parks

At one of our post-polio support meetings, one of the topics mentioned was "what to do if you needed care and your spouse or other family member who normally provided that for you was not available to assist." In other words, help with a capital 'H' was needed and you didn't know where to turn…

In giving further thought to this topic, memories of a nursing home stay reminded me that it might be useful to have written instructions available for use in such an emergency. After all, when a situation like this arises, it is quite possible that anxiety and carelessness will rear their ugly heads, thereby putting us and our emergency caregiver (s) at risk for injury. Therefore, it would probably be a good idea and time well spent to take an hour or two to prepare a written packet containing information that would be helpful to anyone coming in to help on an emergency basis. After all, these people would not have training, would not know our idiosyncrasies such as which leg goes in your underwear first, etc. or whether we get dressed while still in bed or after we are in our wheelchairs or have braces on, etc.

Hospitals and nursing homes frequently have such information readily available to staff in a folder on the back wall of the patient's room. This makes it inherently easier for others coming to assist to get the job done with the least amount of disruption to all. These same items should be readily avail able at home, especially when emergency help might be called in. Some of the points to be made should include such items as:

Where are medications kept? Have an up to date list of names and dosage.

How are you transferred? Do you use a slide board, Hoyer lift or other items; if so, where is the needed equipment kept?

Can you stand up without assistance?

Identify just how you get in and out of bed, on and off the toilet – be specific.

Do you need help showering? Describe what help you need.

Where are your clothes kept? Are they in a certain location for a reason (i.e. easy to reach, in the order that you put them on)?

Do you need help preparing your meals? Do you feed yourself? Be specific with what you can and can't do so there is no doubt about what help you need.

If you have a power chair, where is the wheelchair plugged in and for how long? Are there any special notes concerning its use?

Do you have a Lifeline? Have you equipped your home with a key box that the local police have a key for so that someone can get into your home in an emergency without breaking down the door?

Make sure you have a box of "rubber" gloves on hand. This is not the 1950s and most caregivers will want to have latex free gloves available especially if there is any personal care involved. To be on the safe side get a large size.

Include information in this folder on emergency contacts who may not live in the area in the event there are any problems; also doctors and other healthcare workers who are familiar with you and your needs.

Last, prepare a list of possible emergency caregivers and their phone numbers and keep it in a handy place so it is readily available – in fact, put a copy in your folder with the other information. Then everything will be in one place, and in the event of an emergency, other names will be available, (in addition to the one helping you) if that individual would feel more confident by having another person to assist with your care.

There are probably many other factors to consider when compiling this information, but from personal experience in a nursing home, the folder was invaluable when staff changed (frequently) on how to assist getting me out of bed. It seems like the same principle could apply to our daily lives in our own homes.

The golden years, especially with PPS, seem to be getting a little tarnished, but being proactive helps keep the gold gleaming!

Post Polio Pacer Reporter Injured

Carole Ann Parsons, Post Polio Pacer reporter, suffered significant injuries in an equipment malfunction at her home in July. After spending several weeks in Meriter Hospital ICU, and more weeks at Select Specialty Hospital in Madison, she was recently transferred to Brookfield Rehabilitation and Specialty Care, 18740 W. Blue Mound Rd., Brookfield, WI 53045. Thinking of you cards, prayers and well wishes would be appreciated. No phone calls though as she is unable to speak aloud because of her trach/ventilation system. She tires easily, so if you would like to visit her, please call the hospital (262-782-0230) to see if she is feeling up for having a short visit.

POST-POLIO SUPPORT GROUP MEETINGS

Madison Area Post Polio Support Group— the next meeting is Saturday, November 14. **Long Term Care** will be discussed followed by a question and answer session. **There will be no January meeting.**

The Post Polio Resource Group of Southeastern WI meetings are held at the Easter Seals Kindcare Recreation Center located in Holler Park at 5151 S. 6th St., midway between Grange & Layton Ave., Milwaukee (just north of the Airport Spur). Social time from 1:00 to 1:30 pm.; meeting from 1:30 to 3:30 pm in March, April, May, September, October and November. Check their website at www.pprg.org for dates and program.

The **Janesville Post Polio Support Group** meets from 1-3 p.m. at the Mercy Health Mall, 1010 N. Washington St., Janesville, WI on the first Friday of May, June, August, October and Nov. Contact Art Arnold at UncleBunks@aol.com if you want information on speakers.

The Western Wisconsin Post-Polio Resource Group will meet on October 10 from 12:30 to 3:30 at the Tri-County Memorial Hospital Education Room, Whitehall, WI. Kim Galstad, Registered Dietician, will talk about nutrition. The next meeting will be on April 10, 2010. For more information call Betty Marsolek at 715-985-3801 or e-mail at bmarsolek@triwest.net

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FYI

October is Polio Awareness Month

Hopefully, some of you contacted Governor Doyle to ask him to proclaim October 2009 as Polio Awareness Month in Wisconsin. Help spread information about PPS and the need to have children immunized with the polio vaccine.

Betty Leiser, who recently gave up her driver's license, has for sale her '03 Oldsmobile Silhouette GLS Extended Minivan, 36,000 miles, with all the options and brand new tires. Presently set up and preferred sold as an accessible vehicle with a Bruno Scooter lift. A Sierra front wheel drive scooter included in the price, plus the remaining Quad seats (2), which can be easily installed when the lift is removed. Asking $13,000.00, OBO. Call Betty at 608-222-8897, between 10-12 am or 6-8 pm if you are interested.

PREVENTING COMPLICATIONS IN POLIO SURVIVORS UNDERGOING SURGERY or RECEIVING ANESTHESIA

By Dr. Richard L. Bruno, Ph.D
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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.1,2 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.3 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.1

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 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.4,5 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 non-surgical 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.

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. During surgery, if additional dosing is needed, it should also be reduced while brain waves are monitored.

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 poliovirus-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. 6 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). 4-8 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. 6 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. 9 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.8 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). 4,8

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 fuzzy-headed 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, antiembolism 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 to 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. 2,10,11 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.10

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.10,11 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).11 Certainly, there are few emotional or physical stressor more potent then 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.

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POLIO SURVIVORS' PRE-OP CHECKLIST

Give articles to surgeon and discuss:
O Pre-op lung tests.
O Possibly having lower blood volume and blood banking or bloodless surgery?
O Authorization for a longer stay in the hospital.
O Orders for post-op anti-vomiting medication.
O Positioning on the table during surgery.
O Orders for staying warm in the recovery room.
O Difficulty clearing secretions in the recovery room and on the nursing unit.
O Orders for increased dose of pain medication.
O Phys. therapy for stretching and range of motion in hospital.
O Placing articles about polio in the medical chart.

Give articles to anesthesiologist and discuss:
O Any lung problems
O Lower dose of pre-op calming medication.
O Lower dose of anesthetic.
O Longer-term paralysis of muscles with spinal anesthetic and curare-like drugs.
O Orders for post-op anti-vomiting medication.
O Difficulty clearing secretions in the recovery room.

Give articles to nursing supervisor and discuss:
O Longer-term sedation with anesthetic.
O Difficulty clearing secretions on the nursing unit.
O Orders for increased dose of pain medication.
O Needing help in moving in bed and in the room.
O Not standing or walking until you are fully awake and able.
O Anti-embolism stockings.

Meet with PPS physiatrist before surgery and discuss:
O Post-op rehabilitation plan.
O Physical therapy for stretching and range of motion in hospital.
O Possible admission to a rehab hospital before going home.
O Physical therapy for walking and increasing endurance at home.

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Names in bold are new to the list or have an address change. To add your name and/or up-date your e-mail address to this list, notify Marcia Holman at: wghmch@chorus.net

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POST POLIO PACER is a quarterly newsletter published in January, April, July & October for polio survivors, the Madison Area Post Polio Support Group, health care professionals and interested persons to share information and to promote friendships. Articles in this newsletter are for information; medical advice is always necessary.

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We **need** people to bring new ideas for speakers, topics, books to read and discuss, etc. Call or e-mail (see e-mail list) one of the people listed above to suggest program topics or speakers, volunteer to organize one meeting program, share your knowledge (or find an expert) about becoming a non-profit organization or volunteer your talents (financial, organizing, etc.) as a committee member.

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Give Yourself a Holiday Gift... Conserve Your Energy!

Ask others to help with tasks...
Sit to do tasks when possible
Prep meals in advance
Rest & eat before parties
Shop with a list; rest often

Happy Holidays to all,
Carole Ann Parsons
& Marcia Holman

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A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

Mark your calendars!

LOCATION:

Monona Garden Family Restaurant
6501 Bridge Rd., Monona
Noon to 2:30

Saturday, November 14, 2009
Long Term Care
Speakers will discuss aspects of long term care followed by Q & A session.

NO MEETING IN JANUARY

Golden Rule of Post Polio Syndrome

"If something you do causes you fatigue, weakness or pain, you shouldn't be doing it!"

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