

**The Polio Perspective
July 2013**

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From PHI**

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A Little Bit of Humor

Time for a “Promoting Positive Solutions” from Post-Polio Health, Fall 2010, Vol. 24, No. 2.

Question: A man in our support group who has lived alone for many years is in the hospital. He had stopped cooking for himself, and he is anemic and very run down. He receives supplements and three meals a day and therapy to build up his strength. Another issue (also lived alone for many years) recently moved to a nursing home. How do we know when it’s time not to live alone?

Response from Rhoda Olkin, PhD: This is a great (and possibly anxiety provoking!) question. Of course, polio survivors are not alone in wondering when it’s time to move from living alone to another type of living situation. But we have additional considerations as polio survivors. Let me outline the main reasons people stop living alone, whether the decision was their own, or that of a concerned relative.

A. FALLING. This is one of the main reasons older people move into group living situations. Studies suggest there might be a correlation between depression and falls – and of course we can’t know which might cause the other, only that there is a relationship between the two. I know that when I get anxious or upset, I seem to cut my hands in the kitchen more. Conversely, after a fall I feel fragile and vigilant.

No one knows how often polio survivors fall and what the typical damage is. Perhaps we fall more than people without disabilities, due to fatigued limbs, crutches on wet floors or less agility to recover from stepping on a paper clip on the floor. But certainly any damage we incur from falling can be more serious. We might protect our bodies less when we fall, and atrophied limbs might be more prone to breaking. (And last time I fell when using crutches, I stupidly held onto the crutches and thus fell like a giant tree, flat on my face!)

Additionally, damage to a “good” limb can leave us more disabled. For example, if I hurt my left leg and it couldn’t be weight-bearing, my mostly paralyzed right leg couldn’t pick up the slack, and I wouldn’t be able to use crutches, transfer from wheelchair to the toilet, bed or shower; I would be more immobilized than a person with two healthy legs would be if one leg was injured.

Similarly, if I injured my right hand, not only would I have trouble writing (as would any right-handed person), but I couldn’t use my wheelchair (right-arm control) or crutches, and thus my mobility would be limited to walking (i.e., about 25 steps per day).

So evaluation of our falling history and potential is something we all should be thinking and talking about with our care providers. And please, install grab bars before you need them, and consider a lifeline call button that calls the people you designate in the order you prefer.

B. RISK TO SELF. I hope I’m not the only one getting absent-minded as I age! It’s one thing to lose my glasses, misplace my crutches, forget to pick up my dry cleaning. It’s another thing to leave the stove on until the pot catches on fire, not understand the implications of fire, be unable to take medications as directed or forget to eat. These are more dangerous situations that call for closer monitoring. There are some work-arounds, such as Meals on Wheels, and daily checkin calls. These help, but cannot address all of the issues that can arise.

B. GIVING UP DRIVING. This is a hard one, as most of us think we are better drivers than others think we are. Remember the episode of Everybody Loves Raymond when Debra felt that Frank wasn’t safe to drive the kids anymore? The ramifications in the family were enormous. Driving is equated with independence for many people, and to stop driving seems like giving up.

Much of the United States requires navigation by car. So stopping driving limits one’s social sphere. Not only is it hard to go to the grocery store, library or doctor’s office, but also to visit friends and family. A more communal living situation addresses many of these issues. Additionally, transportation may be provided to organized outings to cultural events.

C. BEING LONELY. Sometimes we curtail our activities without realizing how much we’ve done so. Maybe due to fatigue, you pass on going to a movie with friends one evening, or skip a dinner because it’s a long drive or say no to going to the farmer’s market because it’s too much walking. Or perhaps you are just a “people person,” and you like a lot of social interaction in your life. I love walking into an empty house, but if I were more of an extrovert I might hate it.

Moving to a communal living situation doesn’t have to be seen as a failure to live alone, but rather as a preference for a more social lifestyle. Everyone I know who has made the transition is happy they did so, but most of those same people dreaded

the move beforehand.. So how you feel about the thought of moving is probably different than how you would feel after the fact.

D. BEING ALONE. This is not the same as loneliness. Sometimes circumstances conspire to leave us without family or friends close by. Marriage/partnership, by the way, is the main predictor of going to a nursing home; people with spouses/partners are much less likely to do so. This makes sense. Companionship is a buffer against stress, and there is someone else to notice you left the stove on.

But if you don't have a partner, your kids have moved far away, you commuted to work in a city so your work friends live all over, you don't know your neighbors, then, despite friends and family, you are alone on a daily basis. In that case, all the factors in A – D are more problematic.

E. CHOICES. We may get stuck thinking in black and white terms: living independently in our own homes versus warehoused in a nursing home. Those aren't the only choices. We could live with each other. Or move to a retirement community. There are communities with stepped levels of care. Board and care facilities are smaller homes with only about ten people who live together.

Threaten to live with your kids and I'll bet they can come up with even more choices all of a sudden! But visiting places long before we are even thinking about moving is probably a good idea, so that the image in our heads matches what is really available. And new choices are becoming available.

This is a scary topic for most of us, and we often avoid it until it's inevitable. But you can take control of your future. Before it's forced on you, decide how you wish to live, and communicate your choice to your family and friends or some trusted other. You will feel better making the decision yourself than having someone make it for you. But if the time has passed when you can decide for yourself, trust that being in a more secure environment with other people around will help you feel safer day to day.

THE POST-POLIO LETTER

By Mia Farrow

Basic facts about PPS for polio survivors' doctors, family & friends.

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WHAT ARE POST-POLIO SEQUELAE?

Post-Polio Sequelae (PPS, Post-Polio Syndrome, The Late Effects of Poliomyelitis) are the unexpected and often disabling symptoms -- overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold and pain, as well as difficulty swallowing and breathing -- that occur about 35 years after the poliovirus attack in 75% of paralytic and 40% of "non-paralytic" polio survivors. There are about 2 million North American polio survivors and 20 million polio survivors worldwide. The existence of PPS has been verified by articles in many medical journals, including The Journal of the American Medical Association, the American Journal of Physical Medicine and Rehabilitation and The New England Journal of Medicine.

WHAT CAUSES PPS? PPS are caused by decades of "overuse abuse." The poliovirus damaged 95% of brain stem and spinal cord motor neurons, killing at least 50%. Virtually every muscle in the body was affected by polio, as were brain activating neurons that keep the brain awake and focus attention. Although damaged, the remaining neurons compensated by sending out "sprouts," like extra telephone lines, to activate muscles that were orphaned when their neurons were killed. These over sprouted, poliovirus-damaged neurons are now failing and dying from overuse, causing muscle weakness and fatigue. Overuse of weakened muscles causes muscle and joint pain, as well as difficulty with breathing and swallowing.

HOW ARE PPS DIAGNOSED? There is no diagnostic test for PPS, including the electromyogram (EMG). PPS are diagnosed by excluding all other possible causes for new symptoms, including abnormal breathing and muscle twitching that commonly disturbs polio survivors' sleep, a slow thyroid and anemia. Other neurological or muscle

IS PPS LIFE THREATENING? No. But because of damaged brain activating neurons polio survivors are extremely sensitive to, and need lower doses of, gas and intravenous anesthetics and sedative medication. Polio survivors can have difficulty waking from anesthesia and can have breathing and swallowing problems, even when given a local dental anesthetic.

IS PPS A PROGRESSIVE DISEASE? PPS is neither progressive nor a disease. PPS is caused by the body tiring of doing too much work with too few poliovirus - damaged, oversprouted neurons. However, polio survivors with untreated muscle weakness were found to lose about 7% of their remaining, overworked motor neurons each year.

IS THERE TREATMENT FOR PPS? Yes. Polio survivors need to "conserve to preserve," conserve energy and stop overusing and abusing their bodies to preserve their abilities. Polio survivors must walk less, use needed assistive devices -- braces, canes, crutches, wheelchairs -- plan rest periods throughout the day and stop activities before symptoms start. Also, since many polio survivors are hypoglycemic, fatigue and muscle weakness decrease when they eat protein at breakfast and small, more frequent, low-fat / higher-protein meals during the day.

ISN'T EXERCISE THE ONLY WAY TO STRENGTHEN WEAK MUSCLES? No. Muscle strengthening exercise adds to overuse. Pumping iron and "feeling the burn" means that polio-damaged neurons are burning out. Polio survivors typically can't do strenuous exercise to condition their hearts. Stretching can be helpful. But whatever the therapy, it must not trigger or increase PPS symptoms.

IS TREATMENT FOR PPS EFFECTIVE? Yes. The worst case is that PPS symptoms plateau when polio survivors stop overuse abuse. Most polio survivors have significant

decreases in fatigue, weakness and pain once they start taking care of themselves and any sleep disorders are treated. However, because of emotionally painful past experiences related to having a disability, many polio survivors have great difficulty caring for themselves, slowing down and especially with "looking disabled" by asking for help and using assistive devices.

WHAT CAN DOCTORS, FAMILY AND FRIENDS DO TO HELP? Polio survivors have spent their lives trying to act and look "normal." Using a brace they discarded in childhood and reducing overly-full daily schedules is frightening and difficult. So, friends and family need to be supportive of life-style changes, accept survivors' physical limitations and any new assistive devices. Most importantly, friends and family need to be willing to take on taxing physical tasks that polio survivors may be able to do but should not do. Doctors, friends and family need to know about the cause and treatment of PPS and listen when polio survivors need to talk about how they feel about PPS and lifestyle changes. But friends and family shouldn't take control of polio survivors' lives. Neither gentle reminders nor well-meant nagging will force polio survivors to eat breakfast, use a cane or rest between activities. Polio survivors need to be responsible for caring for their own bodies and ask for help when they need it

Whether you had polio or not, please COPY and MAIL this letter to your doctors. With your help every doctor will learn about the cause and treatment of PPS and give polio survivors the care we so desperately need. Thank you!

Mia Farrow, polio survivor Thaddeus Farrow, polio survivor
Co-Chairpersons The POST-POLIO LETTER Campaign

HOW TO TAME YOUR DRAGON

By Millie Malone Lill

Have you heard the saying, "The best way to defeat an enemy is to make him your friend"? That, I think, is the approach we need to take with the polio dragon. "If you can't beat them, join them" is another useful motto. I know for a fact, that we are never going to beat the polio dragon. He won in the very first round. How, then, do we deal with him?

There are two ways of handling the polio dragon. You can use every motor neuron he left you to keep him at bay. You can drag yourself around on crutches, exhausted and in pain, in order not to let the dragon win by putting you in The Dreaded Wheelchair. Or you can lurch along without the crutches, without your brace or braces, bumping into walls and furniture and, in your own mind, not looking as though you are handicapped. To other people, you probably look like a drunk or like someone who is severely handicapped and in denial. It causes them to pity you. I don't mind compassion, but I hate pity. This method is not very effective.

The other way is the way karate students are taught. Use your opponents attack as your defense. In other words, roll with the punches. This keeps your opponent off balance. Instead of fighting to stay out of The Dreaded Wheelchair, embrace it as a friend. You

might discover that it really isn't The Dreaded Wheelchair, but the Blessed Wheelchair. Oh, there will be times, when you are out and about and forgot to charge The Blessed Wheelchair and you will bless it and yourself in a loud voice. All blessings are a bit mixed, after all.

This is not to say the polio dragon will be defeated. No, sad to say, that won't happen. It might make his swipes at you less effective, though. He destroyed so many neurons right at the outset of the battle that you have a very sadly depleted armory and no way to buy more. His goal now is to make you, yourself, destroy the rest of your weapons. Every time you exhaust yourself in fighting this dreaded foe, you use up more of your resources. Every time you use an assistive device, you conserve a bit of your dwindling supply. It only makes sense to go into a siege mind set. Hoard your weapons, saving them only for defense.

This dragon would like nothing better than to see you totally defeated, all motor neurons burnt to a crisp, not one muscle left in useable condition. If you want to at least stop his damage, you have to fight smarter, not harder. Take a nap when you need one. Say NO to activities that require you to do things that are exhausting or too difficult. Wear a smile as armor against those who don't understand that when you say you can't do something, it means you cannot, not that you will not. Be firm, but pleasant. Don't try to deny that the dragon has damaged you, but don't let him do further harm.

Eventually, you and the dragon can sign a peace treaty. If you don't continue to fight him, he won't have occasion to strike out at you. Maybe you can even reach a point where you use his fiery breath to roast hot dogs and marshmallows.

Web Corner

An ongoing blog with posts from various disabled people

<http://www.rollingwithoutlimits.com/>

Polio Virus Spreading in Mogadishu

<http://postpoliospain.blogspot.com.es/2013/06/a-number-of-new-polio-cases-have-been.html>

Health Benefits of Garlic Tea:

<http://www.livestrong.com/article/256060-health-benefits-of-garlic-tea/>

Human Limb Regeneration...Fingernails Hold Clues

<http://www.disabled-world.com/assistivedevices/prostheses/regeneration.php>

Interesting Symptom Site

<http://www.neurosymptoms.org/>

Another PPS Newsletter

http://www.ppsmanager.com/PPSM_2013/PPSM_05-13.html

Medical Article List Updated

<http://i-sites.net/ppsma/medindx.html>

Coping With Excessive Sleepiness

<http://www.webmd.com/sleep-disorders/excessive-sleepiness-10/emotions-cognitive?page=2>

Non Prescription (Non Lethal) Pain Treatments

<http://www.undergroundhealth.com/non-prescription-alternative-pain-treatments/>

Piece of medical history on display in Deadwood

<http://www.blackhillsfox.com/2013/05/23/Piece-of-medical-history-on-display-in-Deadwood>

A Little Bit of Humor

Missing Person

A distraught wife went to the police station with her next-door neighbor to report that her husband was missing.

The police asked for a description of the missing man.

His wife described him as 6' 4" tall, dark wavy hair, athletic build, weighs about 180 and very friendly and soft-spoken.

The neighbor interrupted. "But he's 5' 8", overweight, bald and is very loud and obnoxious.

The wife sighed. "Yes, but who wants HIM back."