

The Polio Perspective
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A graphic from Asociacion Post Polio Litaff A.C.

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A QUESTION OF SEMANTICS

By Kathryn Kniep

Crippled always sounds to me
Like a piece of paper that's been folded wrong
No sharp crease, instead
Crumpled, lumped and bumpy
Marked with a network of inexperienced lines
From repeated efforts to fix it
Run your finger over it,
You can feel the edges lifted like a scar.
Handicapped's ok, but better in bowling
Disabled has the breath of the sick room
Invalid, after all, translates to in-valid.
If you must call me something, I'd prefer
Person who has survived great pain
With more courage than she had
And more strength than she could muster.
Still, even I'll admit that's a little long
To print on a parking pass.
So shorten it.
I'll settle for "Person".

CONSTIPATION NATION?

I've gotten a bunch of e-mails on constipation. Polio survivors have slow guts, thanks to poliovirus-damage to the vagus nerve that should fire to move food from your mouth all the way through to the other end (see articles in The Post-Polio Library at <http://www.postpolioinfo.com/>). Here are some things about constipation you may not know:

1) Constipation isn't one thing. Sometimes poo gets stuck in the ascending colon on the right side of your belly, sometimes in the transverse colon across the top of your belly, sometimes in the descending colon on your left side or in the rectum. So, you have to focus treatment where constipation occurs.

2) Not all laxatives work in the same way or in the same place:

- > Roughage and Senna irritate the whole colon to make it move;
- > Miralax and Colace add water to your poo to "lubricate" the colon;
- > Dulcolax stimulates the ASCENDING colon if you get plugged there;
- > Psyllium absorbs water and expands to stop diarrhea but also combines with sludge to make one single poo (and not lots of little "rocks") that itself stimulates the colon naturally to make things move. (You should plan to sit on the throne after eating to take advantage of the natural stimulation caused by food in the colon);
- > Suppositories are for rocks in the lower colon and rectum.

3) If nothing is moving, your stomach isn't emptying or the colon won't respond to the above treatments, there is a great drug -- domperidone (sadly NOT Dom Perignon) -- that directly turns on the muscles that empty the stomach and move the colon. Domperidone

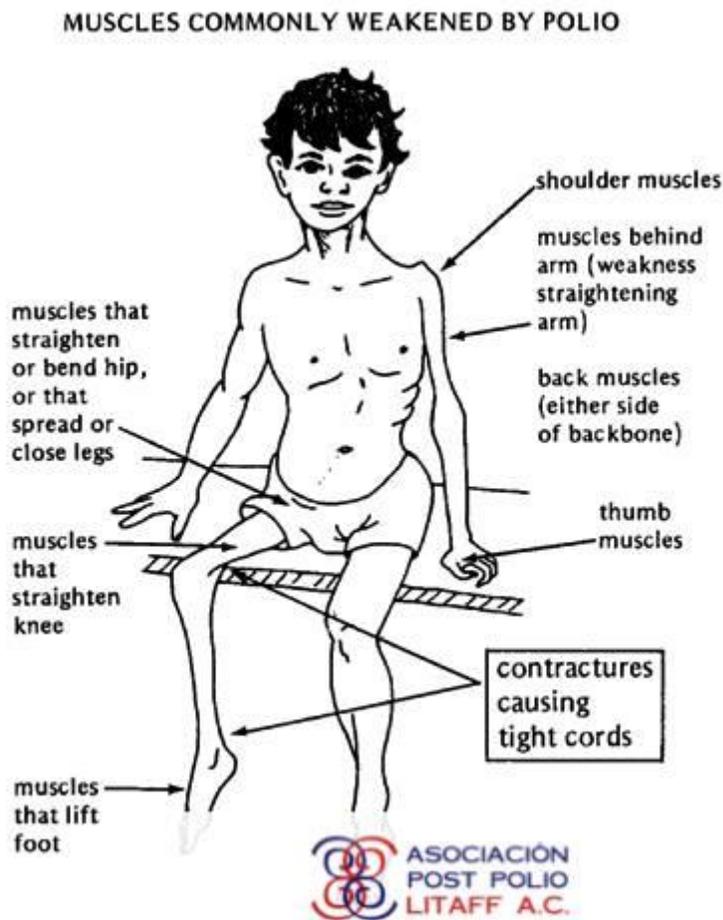
has no side effects and doesn't enter the brain (as does Reglan, which can cause Parkinson's-like shaking and should not be used by polio survivors). Of course, the FDA hasn't approved domperidone even though it's been sold over the counter for 20+ years in Europe for nausea during pregnancy! (Apparently, not enough payola to the FDA.) You CAN get domperidone from Canada with an Rx.

So, there's a short course on pushing poo. You may need a combination of treatments or different treatments at different times for different types of constipation.

Keeping a poo diary (quantity, quality and time of day) that includes symptoms and what laxatives you've taken is vital so that you can identify your natural rhythm, where things get stuck and what you need to take to make things work.

Happy eating (and the other thing).

The Prince of Poo...ah, I mean Polio



Slow Guts and Polio Survivors

***By Dr. Richard L. Bruno
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<<I have trouble swallowing but no one believes me. Food doesn't get stuck in my throat, but seems to lodge somewhere behind my breastbone. I had a normal swallowing study and the doctor doesn't believe I have a problem. But, food sticks and it hurts when it does! Do other polio survivors complain about this?>>

They surely do. It's hard enough to "swallow" having PPS without doctors refusing to believe you're having trouble swallowing.

It's true that most Post-Polio Institute patients report having only occasional, mild problems swallowing. The problem is usually high in the throat: not being able to get down pills, largish pieces of meat and, maybe even more often, difficulty clearing their own secretions. A barium swallow study (where you eat and drink food containing barium and "video" is taken with an X-ray camera) usually shows mild muscle weakness in the throat or sometimes, as in your case, no problem at all. This "negative" finding is just like a muscle test of an arm or leg not showing weakness in the doctor's office, even though you feel weaker or even stumble at the end of the day as you get more tired.

Polio survivors also have swallowing problems below the throat. What you describe -- food getting stuck behind your breastbone in the esophagus (the tube connecting the throat to the stomach) is not uncommon in polio survivors. The muscles of the throat and esophagus should contract in a coordinated sequence, like a snake, to move the food downward and into the stomach. Food gets stuck when the esophagus doesn't contract and its muscles go into spasm, not unlike when back muscles go into spasm when your leg muscles are too weak to hold you up. Food usually gets stuck right behind the top of the breastbone. And, yes, stuck food is painful...and scary! Even if food does make it down to the bottom of the esophagus, in some polio survivors the "valve" at the bottom of the esophagus doesn't open and prevents food from entering the stomach, a condition called achalasia.

Why do polio survivors have trouble with muscles from their throats to their stomachs? Fifty years ago, Dr. David Bodian discovered that every polio survivor had some damage to neurons in the brain stem, the so-called "bulb" of the brain. When brain stem damage was severe and "breathing neurons" stopped working, "bulbar polio" was diagnosed. But

the most common bulbar polio symptom was trouble swallowing not trouble breathing, because the poliovirus also damaged the bulbar neurons that control the vagus nerve, the nerve that activates and coordinates muscles from your throat down to your stomach.

Unfortunately, 99% of gut doctors have never seen food get stuck in the esophagus and don't know what to do about it. We've found that a low dose of the muscle relaxants Klonopin and Bentyl, taken 30 minutes before eating, can relax the esophagus and allow food to slide down to its intended destination.

But wait! There's more! Vagus damage likely explains our 1985 Post-Polio Survey finding that diarrhea, colitis, ulcers and constipation are as much as six times more common in polio survivors than in the general population. Some polio survivors report that their stomachs don't empty, a condition called gastroparesis. Other have their intestines abruptly stop moving -- as a side effect of medication, after surgery, a gall bladder attack, or for no reason at all -- a condition called paralytic ileus. Often, the muscles of the stomach and intestines get moving again on their own. But, sometimes the drug Reglan is needed to jump-start the stomach and intestines. Reglan can have bad side effects, since it enters the brain. DOMPERIDONE, a drug that does not enter the brain (or the US, so you have to buy it from Canada) is the better choice if you can take it by mouth). Also, polio survivors need to try to prevent gut slowing by being careful when taking drugs that are anti-cholinergic (drugs that have dry mouth as a side effect) since they block the activity of the vagus nerve.

Finally, polio survivors who have a chronic sore throat, husky voice, or burning in the chest should be evaluated for reflux by an ENT doc, who'll look at the upper throat and vocal cords, and a GI doc, who may do a gastroscopy to look down your esophagus and into your stomach. If you have a gastroscopy, make sure that the doctor goes light on the anesthesia and uses the anesthetic Propofol, since it's short-acting and allows polio survivors (usually) to wake quickly.

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Square Pegs, Round Holes and Pigeonholes

By Millie Malone Lill

For most of my life, I've been a misfit. If the Round Hole was big enough, I could sort of fit in, but there would be noticeable gaps on top, bottom and sides. In school, I was not teased or tormented because of my limp but I was only accepted in a limited sort of way. It was understood that certain things were not available to me. No one ever explained the why or wherefore of this, but I believed it. I just accepted the fact that while the other girls my age were swooning over the football players, or going out for cheerleading or homecoming queen, I was expected to be a spectator. My mother also assured me that I was unacceptable as marriage material, so dating would be an exercise in futility. No one would ask me, anyhow, so it was moot.

As I got older, I noticed the before unseen gaps in the Round Hole around my square person. When a guy asked me to get married right out of high school, I accepted. I knew no one else would ever ask and that if I wanted a family, I better catch this train before it left the station. Although I got very good grades in school, college was out of the question. It was not even considered for me. I was only good enough for marriage, not for a career.

My marriage, fortunately, was a happy one. I loved being a mommy and I loved being a wife. I filled the gaps in the Round Hole with children, my own and as many of everyone else's as were available. We had a good team going, my husband, myself, and our three sons. Unfortunately, my husband's health failed him shortly after we married. His appendix ruptured and he nearly died. That was the first of eight separate times that I was told he would not make it. The eighth time arrived too soon and I was a widow at age 52.

I'd been given a computer by my Vocational Rehabilitation counselor and urged to learn to use it. I started classes at Western Iowa Tech, a community college about 10 miles from my farm. I fit in better there, despite the vast age difference between me and most of the other students, than I had in high school. I loved it. I learned a lot about computers and learned how to use the Internet.

The Internet! I did a search for Post Polio Syndrome and found an online support group. To my surprise, I found an unlimited number of Square Pegs! Here was the Square Hole I'd been looking for my whole life. No gaps, top, bottom, or sides. Nope. I fit in perfectly. I was accepted completely. The novelty of that nearly knocked my socks off.

Starting then, in 1996, I was part of what I've come to see as my polio family. No need to explain to them why I could not go dancing or hiking or stand in line for extended periods. They knew. They couldn't, either. My blood family might raise an eyebrow if I skipped a funeral because the church was not accessible, but my polio family didn't blink an eye.

Even my writing finally had an outlet. I wrote columns for Gleanings, the newsletter for the Nebraska Polio Survivors Association, and later I started doing an online polio newsletter. There were still times that people wanted to stuff me in a pigeonhole labeled INVALID, but I refused to stay there. No, just because I use a power chair does not mean that my mind doesn't work. And no, just because I can walk a little bit, it does not mean that I'm 'giving in' if I use my chair.

I am very much enjoying the Square Hole I live in now. I've wiggled around in it enough to round its edges as well as my own. It is neither Round nor Square at the moment, and it definitely is not a pigeon hole.

WEB CORNER

An article on Post Polio;

<http://www.pfmc.co.uk/Library/Conditions/Articles/polio-and-post-polio-syndrome-/diagnosis>

Chronic Pain, Addiction and Zohydro

<http://www.nejm.org/doi/full/10.1056/NEJMp1404181?query=TOC&#.U11Y-0wQbU.facebook>

Epidural Injections May Cause Problems For Those With Neurological Diseases;

<http://www.jwatch.org/fw108750/2014/04/24/epidural-corticosteroid-injections-pose-risk-neurological>

Mia Farrow's Post Polio letter plus lots of other good information:

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

Polio in the News:

<http://newswatch.nationalgeographic.com/2014/04/20/geography-in-the-news-polio-returns-with-tenacity/>

Video: "Celebration of FDR's founding of the March of Dimes"

http://www.poughkeepsiejournal.com/article/20140411/NEWS/304110036/VIDEO-FDR-s-legacy-lives-Exhibit-celebrates-his-founding-March-Dimes?nclick_check=1

One-Legged Wonder:

<http://www.stuff.co.nz/national/9921057/One-legged-acrobat-was-world-famous>

Second European Polio Conference

http://cordis.europa.eu/news/rcn/36516_en.html

Disability Resources:

<http://www.dol.gov/dol/topic/disability/ada.htm#.UzyMSyaDoWg.facebook>

The Best Exercises for Polio Survivors:

<http://www.livestrong.com/article/410542-the-best-exercises-for-post-polio-patients/>

A LITTLE BIT OF HUMOR

The Black Belt

Hank was not too bright. Everyday when he walked home from work, he would get stopped by three nasty men and they would beat him up and steal his money.

Finally, Hank decided that it would serve his best interest to walk a different route and then take up some self-defense classes so this wouldn't happen again. He joined a karate class and soon was doing very well to defend himself.

So, one day, on the way home from work Hank took his old route home and sure enough there they were. He walked up to them and the battle ensued. The next afternoon Hank went to his karate class with a black eye, a broken nose and a busted lip.

His instructor, shocked, asked him what happened.

"Well," explained Hank, "I took my old way home last night so I could beat these guys up who were stealing my money, but they beat me up before I could get my shoes and socks off!"