

POLIO PERSPECTIVE

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Simple Remedies for Constipation

By JANE E. BRODY

Chronic constipation is an all-too-common problem rarely discussed in polite company and only reluctantly mentioned to doctors during checkups. Although it accounts for eight million doctor visits annually, only “a minority of those with constipation seek medical attention,” Dr. Arnold Wald, a leading expert on the problem, reports.

Yet this hesitance can perpetuate mistaken beliefs about its consequences, causes and treatment, and often results in failure to get effective relief. Most of the time, relatively simple treatments prove adequate. Even more complex cases, like those that involve a disorder of muscle action in the pelvis, usually respond well to currently available remedies.

Chronic constipation can accompany a long list of medical problems – mechanical ones like a stricture or tumor; neurological disorders like Parkinson’s disease or multiple sclerosis; or metabolic conditions like severe low thyroid or low blood levels of magnesium.

Constipation can also be a side effect of medications, especially opiates like Percocet and OxyContin, as well as some antidepressants, anticonvulsants and antihistamines.

As someone who has dealt with constipation, with varying degrees of success, for most of my life, I had more than an academic interest in learning more about it. Hence this column, prompted by a friend's excruciatingly painful problem that seemed to emerge from nowhere and by a new review of studies on the topic published in JAMA by Dr. Wald, a gastroenterologist at the University of Wisconsin School of Medicine and Public Health.

Many strongly held beliefs about constipation are not based on medical evidence, Dr. Wald and his colleagues have noted.

One of the oldest yet most persistent of these unsubstantiated notions is that failure to empty one's bowels each and every day can result in so-called autointoxication – the absorption of poisonous substances produced from partially digested food and food byproducts in the intestines. Through the years, autointoxication has been erroneously blamed for a host of ailments, including high blood pressure, arthritis, atherosclerosis, gall bladder disease, various cancers and skin disorders.

Autointoxication is often cited as a reason for the common but mistaken belief that a daily bowel movement is essential to good health. But there's no evidence that food that sits in the intestine leads to the buildup of toxins. The medically accepted definition of constipation is "fewer than three bowel movements a week, or hard, dry and small bowel movements that are painful or difficult to pass," often resulting in abdominal pain or bloating.

Unfortunately, as a college freshman, I met those criteria. An astute physician provided advice that has helped to minimize the problem ever since. She gave me a list of "constipating" foods to avoid – white rice and other refined grains, unripe bananas, tea, cheese and chocolate – and even more important, foods to eat regularly: beans, whole grain cereals (especially bran) and breads, vegetables, fruits (especially dried fruits) and nuts. Eating more of these and other high-fiber foods can be very effective in curbing constipation. And she recommended drinking a full glass of water before bed to help soften the stool and another after awakening to stimulate my bowel.

Following this advice I've never had to rely on laxatives, although those medications are associated as well with myths and misconceptions that are important to dispel. One mistaken belief Dr. Wald and others have cited is that long-term use of stimulatory laxatives like senna and bisacodyl (Senokot and Dulcolax, respectively) can impair normal function of the colon and cause dependency on the medication.

While it is true that using stimulatory laxatives for many years at more than a dozen times the suggested dosage can damage the colon's nerves and muscles, Dr. Wald and others say that properly designed studies of these laxatives have shown no harm to the colon when they are taken in recommended amounts.

Yet many doctors still warn – inappropriately, Dr. Wald says — against taking stimulatory laxatives for more than a few days. Indeed, the website FamilyDoctor.org states, "When these laxatives are taken for a long time, the bowel can lose its muscle tone and 'forget' how to push the stool out on its own." Best to forget this outdated idea as long as you stick to the recommended dose if you must take these products.

Short of potent laxatives, other milder remedies often prove helpful. One is exercise, the more vigorously done the better. Another is to establish a regular bathroom time and respond promptly to the urge to defecate. I am among many who have found that a large cup of hot coffee in the morning is often a very effective stimulus.

However, as my ability to prevent constipation has diminished with age, I've added two other over-the-counter aids: a daily soluble fiber supplement of psyllium dissolved in juice or water (other fiber products like methyl cellulose, calcium polycarbophil and wheat dextrin can also be effective) and a twice-daily dose of a stool softener, both of which can safely be used indefinitely.

However good dietary fiber normally is for maintaining a healthy gut, it can be harmful when the cause of constipation is muscle weakness or a nerve problem, Dr. Wald said. Such patients often do better by eating less fiber and instead taking a secretory drug like lubiprostone (Amitiza) or linaclotide (Linzess) that adds water to the colon and softens the stool.

Sometimes, too, standard remedies for chronic constipation are ineffective. None worked for my friend, a New Yorker who suddenly developed an extremely painful problem at age 73 that was finally diagnosed as a failure of her pelvic floor muscles to relax when they are supposed to and allow the stool to pass through. Instead of relaxing, the muscles around the rectum contract. "It is a learned unconscious act that can be unlearned," Dr. Wald explained.

Despite the usual remedies of diet, exercise and a costly prescription-only stool softener, the problem has recurred every eight days or so, she said. She is now being treated with deep breathing exercises 10 times a day and abdominal massage above the colon twice a day, and has begun biofeedback to "retrain" the muscles that are responsible for normal colorectal action. Dr. Wald said that biofeedback training, when done properly, is effective in about 80 percent of cases.

My friend's experience underscores the importance of consulting an expert when constipation persists and fails to respond adequately to self-help measures of diet, exercise and over-the-counter remedies.

Bruno Bytes - February, 2016

On the topic of an EMG and PPS Diagnosis (2/1/2016)

Original Post: I am going to PT, walking on boot, and omitting crutches and walker more and more now. Would it be best to see him while this heals, or to wait until I am back to "normal" for me? I'm going to a new doctor. What tests are involved? Are there EMG's? Ouch!

Dr. Bruno's Response: NO EMG unless they are looking for other than PPS. EMGs CANNOT DIAGNOSE PPS, but can show an old polio.

On the topic of Pulmonary Embolism (2/4/2016)

Original Post: Is Pulmonary Embolism connected to PPS?

Dr. Bruno's Response: Fortunately not. For more than 33 years of treating polio survivors we have never had one who had had a pulmonary embolus. Even though polio survivors feeder often purple and blood pools when it's cool or cold, the blood does indeed flow back to the heart and doesn't stay in the limb to clot, so there is no predisposition to having blood clots in the legs moving to the heart and lungs.

2nd Post: The lack of activity and especially legs that don't work anymore. Does that cause swelling?

Dr. Bruno's Response: Lack of activity can cause swelling especially when the weather is warm.

If you remember there was a huge outcry a few years ago about people on flights from the US to

Australia developing blood clots in their legs and then pulmonary embolisms. Everyone was told to move their feet up and down and to walk as often as they could. If *just* flying to Australia did cause blood clots, every polio survivor who has used a wheelchair since 1952 because both lower legs were paralyzed should be dead due to blood clots in their lungs and brain!

On the topic of Bladder Control (2/6/2016)

Original Post: This is a little bit awkward but I wonder if anyone has "accidents" sometimes...this morning I woke up because I had peed. Could this be polio-related because of my bladder muscles becoming weaker?

Dr. Bruno's Response: Polio could make bladders problems worse but typically it is not the main cause. See your doc and have a urinalysis. It could be a UTI.

Is "Type A" Behavior CRIPTONITE? Painful Confessions of a SuperCrip by Dr. Richard Bruno

Last October, I wrenched my shoulder getting my chair out of the car. Man, did it hurt! I could hardly transfer. Each time I did something strenuous the pain inched up a notch. Soon, my shoulder was too painful to do ramps or push on a rug. Ultimately, I could hardly push at all. Did I go to a doctor? No way! I didn't need no stinkin' doctor! I just kept on keeping on. I had places to go and things to do, do, do!

Then I read a magazine story about doctors with disabilities. One of the doctors interviewed struck a "chord" when she summarized her philosophy about having a disability with this statement: "It only matters what you do." It only matters what you do? She was describing me, wasn't she? By ignoring my painful shoulder, I was acting as if "doing" is the right way--maybe the only way--to deal with a disability. Do other people with disabilities just ignore what they feel and keep on "doing?" When you look around, it sure seems that way.

The Type "A" SuperCrip: Doing versus Dealing

There's a lot of information about how North America's most experienced group of crips--the 1.8 million survivors of the polio epidemics of over 40 years ago--deal with disability. Polio survivors work more hours of overtime and are more Type A--that is, hard-driven, pressured, time-conscious, perfectionistic and overachieving--than any other group with or without disabilities. Polio survivors, regardless of the severity of their disability are often the leaders, movers and shakers of our communities.

What's wrong with being a hard driving, Type A community leader in a wheelchair? Dr. Nancy Frick, polio survivor and Executive Director of Harvest Center in Hackensack, New Jersey, says that Type A behavior is literally burning polio survivors out. "Our surveys show that the more Type A polio survivors are, the more likely it is they will have Post-Polio Sequelae--late-onset fatigue, weakness, muscle and joint pain and the more severe their new symptoms will be."

What's worse, being Type A prevents polio survivors from getting treatment for their PPS. Even though polio survivors realize that burning the candle at both ends is causing pain and loss of function, they just can't slow down. Polio survivors will ignore even excruciating pain for years to avoid "wasting time" by going to the doctor. So for many polio survivors, pain doesn't matter. All that matters is what they "do."

But it isn't just polio survivors whose super Type A behavior gets in the way of dealing with their pain. In one study, 40 percent of patients who had chronic back pain were discharged from treatment or quit therapy on their own because they were "just too busy" to feel better. Again, the more Type A the pain patients, the less willing they were to stop "doing" and start managing their pain.

Use It or Lose Everything?

Why would people push themselves beyond their physical limits, experience constant pain, and even permanently damage their bodies to just keep doing? Among those of us with disabilities, "doing" may be how we prove to the world that we're as good as or even better than non-disabled people.

A lifetime of physical excess is described by polio survivor Dave Graham. Graham is a full-time commission salesman and organist for two professional baseball teams in his spare time. "From my earliest recollections, I was competing to be as good as or better than able bodied people around me," says Graham. "I pitched softball for many years. Although my left arm and leg were atrophied, my right arm was huge. Everybody told me how great I was because my handicap didn't hold me back. I reaped the praise and did almost everything with a vengeance. Unfortunately, this behavior has shortened my span of physical productiveness. Now I hurt 24 hours a day."

"Jack," a disability rights activist, wheelchair athlete and T10 para, is proud to be an aggressive overachiever: "Some say disabled people have to overachieve just to 'break even' and be as good as ABs. I overachieve so that the ABs know I am better than they are! When an AB discriminates against me, dismisses me with a pat on the head, I think to myself, 'Go ahead, jerk. Did you graduate first in your college class? Have you been on TV? Have you met the Prime Minister?'"

Denial Ain't Just a River In Egypt

There may be yet another explanation for Type A SuperCrip behaviour: denial. If you can't be accepted by society with your disability, why not just deny it? Says Rick Korejwo, a writer with multiple sclerosis, that's just what SuperCrips do. "People who push hard against the reality of their disability and refuse to give it any quarter are perhaps physically overdoing as a means of denial."

Writer and power wheelchair-user Jesse Kaysen thinks this sort of denial may be gender-driven. "Men may be especially prone to physical denial of disability because of the pressure of machismo in our culture. What's worse, it's the adventurous, headlong, 'macho' kind of guys who tend toward fast cars, hang gliding and other good opportunities to break their necks in the first place.

"Men born with a disability or who are disabled early in life," continues Kaysen, "are also prone to physically overdoing to prove that they're 'real men' in this society where manhood is equated with physical ability."

This notion is supported by Dr. Frick's findings that the more physically disabled and the younger survivors were when they had polio, the more Type A they are as adults. So there seems to be a relationship between being disabled at a young age and becoming a Type A SuperCrip later in life. The need to demonstrate physical prowess to distract from one's disability may in part explain the appeal of wheelchair sports. No man is more accepted or revered in our society than The Athlete. The Athlete knows that there is no gain without pain, lives to "feel the burn" and is conditioned to play even when hurt. After all, a "real man" doesn't give in to pain.

Athletic trainer Carrie Ann Lucas, who also has a physical disability, warns that the majority of injuries to wheelchair athletes, and to wheelchair users in general, result from overuse. "Overuse injuries to the hands, arms and shoulders," she says, "occur when athletes train too hard or return to training or competition after an injury even though they are still in pain."

Lucas says that for each day an athlete ignores pain, two days are added to the time it takes to actually recover. "And it's frightening," she adds, "that a third of wheelchair athletes don't seek treatment when they get hurt."

All of this Type A behavior in athletes raises a question: Are competitors acting solely out of an interest in sport or a compulsion to prove, at any cost, that they're not really disabled?

SuperCrip: Compulsion or Choice?

Many Type A wheelchair users may be willing to pay the price of physical pain and loss of function to make themselves and the non-disabled people around them forget that they're disabled. This sounds more like a bargain with the devil than an appropriate means of dealing with a disability. But there are those who endorse the Type A SuperCrip lifestyle. Charles and Linda Gray, an occupational and a physical therapist, respectively, are polio survivors. They agree that Type A people may tend to wear out quicker. "But," they say, "it's the quality of life that matters. We feel we have lived life to the fullest."

Words of conciliation come from Laura, who uses both manual and power wheelchairs: "I think being Type A is more multidimensional than it may appear. People become Type A for many reasons. For some it is overcompensation. Others push their bodies and minds in the context of fully accepting, even loving, themselves and their disabilities. Being Type A is just a path they choose to follow." Laura frames the question we all must answer: Is being Type A really a path we choose or are we on automatic pilot, overusing and abusing our bodies so that we don't have to face the emotional and physical realities of our disabilities?

All arguments aside, common sense tells us that we do on auto pilot to blunt the emotional pain of having a disability probably isn't good, whether it's drugs, booze or an addiction to "doing." Ignoring constant physical pain and even damaging our bodies is no way to love ourselves or our disabilities...

Last week I took an hour out of my Type A day and started physical therapy. I felt nervous, a little scared, actually--wasting time that I could have used to do something productive. But you know what? My shoulder hurts less and I actually feel less disabled because I can push myself down the hall without screaming.

I know that what I "do" should arise from my thoughts and feelings, not serve to bury them. But I know too that it's frightening to slow down, ask for help and risk feeling. or God forbid looking more disabled. But it's my body and I am responsible for how it feels and what happens to it, today and long into the future. Maybe seeing "Superman" himself "flying" around in a power chair will remind me that he, and we all, are "super" because of who we are, not because of what we "do."

Dr. Richard L. Bruno, a wheelchair user since 1986, is chairperson of the International Post-Polio Task Force and director of The Post-Polio Institute and The International Centre for Post-Polio Education and Research at Englewood (New Jersey) Hospital and Medical Center.

Take the Type A Test:

If you answer "yes" to more than four questions you are Type A and probably don't stop doing long enough to take care of your body or to treat your pain:

I enjoy competition.

I have a temper that is hard to control, "fiery."

I set at least one deadline a day for myself.

I set at least one deadline a week for myself.

I spend more than eight hours a week doing overtime work at home.

I am "hard-driving."

It's very important for me to get ahead in life.

I have taken less than one vacation a year in the last five years.

I take less five days on an average vacation.

It's very important for me personally to get ahead in life.

Are you Crazy? *By Millie Malone Lill*

No? Neither am I, but many of us when we first exhibited signs of PPS were told maybe we needed to “talk to someone.” That's code for “You need a psychiatrist.”

- “It's all in your head,” we were told.
- “There's no such thing as PPS” “
- “PPS does not cause pain”
- “Use it or lose it”
- “Of course you are depressed. Get some exercise and you'll feel better”

Since polio survivors are usually people pleasers, we tried. We tried really really hard not to be so disabled, tried not to limp. We tried to ignore the fact that we were almost always exhausted. And in many cases, we tried to exercise. In spite of the fact that whatever we do takes about 3 times the energy as it does for an able bodied person, we persevered.

Maybe because we became very proficient at planning things out so that we could do them in the most efficient manner, we became the “go to” people in our families. We did the planning for family reunions, we did anything that anyone else couldn't/didn't want to do. Dealing with our own frailties made us more compassionate toward others, so we became the care givers in our families, too.

Some of us, I for one, were taught not to complain, no matter what. We were not to make other people feel bad about our problems. “Don't expect others to help you. Learn to do it yourself. You can do it, you just aren't trying hard enough.” Sound familiar?

Of course, when we first contracted polio (and by the way...contracted? I don't remember signing any darn contract for this! And even if I had, I was four, under age, doesn't count. Is that a loophole?) nothing was known about post polio. It was thought that we were totally recovered and that was that. We did recover. We became “normal.” Or at least it appeared that we did. In actual fact, we were using up our resources to the point that we were pretty much guaranteed to get PPS.

This caused a double whammy for us. Not only were we running out of motor neurons to burn up, but as we became more and more disabled, our families were becoming more and more confused. Here you are, the person everyone turned to when they needed help and you say you can't do it! You did it last week/month/year and now you say you can't? What do you mean, you can't? Of course you can!

So you force yourself to do it one more time. Ooops, not a great plan as that last little motor neuron just hit the BBQ. That was the neuron your left leg was counting on in order to be able to help you lurch across the kitchen to cook supper. Oh well, you can hang onto the countertop and manage to get to the fridge, the stove, the sink. How you actually get that food on the table is another problem. Hmmm. If I put the food on a tray, put the tray on that wheeled bar stool...but there isn't room for everything on the tray and I don't think I can make another trip. That left leg has just left the building.

You know, maybe we are crazy. Have you ever noticed that people who did not get polio have little or no problem asking for help when they need it? Other people can form their lips into that circle that allows the word NO to come out, loud and clear. Now there's an exercise that would actually be good for us. Everyone, pucker up, put your tongue on the roof of your mouth and...altogether now...NO!

Did that hurt? Didn't think so, well, maybe just a little around the pride area and maybe a slight ding in the old ego. Nothing that a nice little snooze in the recliner while someone else cooks supper won't help.

Our families need to understand that we have done our share and then some. It's time for someone else to pitch in. Since we do know all the most efficient ways to do things, we can teach them to others while we save a couple of tired old motor neurons for our old age.

WEB CORNER

Post-Polio Syndrome: A Guide to Management

<http://www.britishpolio.org.uk/polio-and-post-polio-syndrome/information-for-healthcare-professionals/post-polio-syndrome-guide-management/>

Depression, an Allergic Reaction to Inflammation?

Pennsylvania Polio Survivors Network <http://www.papolionetwork.org/>

Prescription Assistance:

http://www.needymeds.org/pap?utm_source=February+2016+PAN&utm_campaign=August+2015+PAN&utm_medium=email

An Adapted Van: James Bond Would Love It

<http://www.sunnyrollerblog.com/adapted-van-james-bond-love/>

Inspiration for our Spirits

<http://www.papolionetwork.org/inspiration-for-our-spirit.html>

This Designer Revolutionized the Crutch

<http://mentalfloss.com/article/74297/designer-revolutionized-crutch>

Implementing the Affordable Care Act: A Road Map for People With Disabilities

<http://www.ncd.gov/publications/2016/implementing-affordable-care-act-aca-roadmap-people-disabilities>

Hard to Swallow

<http://quest.mda.org/article/hard-swallow>

Stress Will Bring You Down

<http://www.myragoldick.com/4752/stress-will-bring-you-down/>

New Anti Polio Vaccine Likely to Yield Positive Results

<http://postpolioprobblemadediscapacidad.blogspot.com/2015/04/new-anti-polio-vaccine-likely-to-yield.html?pref=fb>

NEWSLETTERS ONLINE

Pennsylvania Polio Survivors Network

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

Post Polio Health

<http://www.post-polio.org/>

Polio Association

<http://www.polioassociation.org/newsletters.html>

A LITTLE BIT OF HUMOR

A wealthy old lady decides to go on a photo safari in Africa, taking her poodle along for company. One day the poodle starts chasing butterflies and before long, discovers that he's lost. Wandering about, he notices a hungry-looking leopard heading rapidly in his direction. The poodle thinks, "Oh, oh!" Noticing some bones on the ground close by, he immediately settles down to chew on the bones with his back to the approaching cat. Just as the leopard is about to leap, the poodle exclaims loudly, "Boy, that was one delicious leopard! I wonder if there are any more around here?" Hearing this, the leopard halts his attack in mid-strike, a look of terror comes over him and he slinks away into the trees. "Whew!", says the leopard, "That was close! That poodle nearly had me!"

Meanwhile, a monkey who had been watching the whole scene from a nearby tree, figures he can put this knowledge to good use and trade it for protection from the leopard. So off he goes, but the poodle sees him heading after the leopard with great speed, and figures that something must be up. The monkey soon catches up with the leopard, spills the beans and strikes a deal for himself with the leopard. The leopard is furious at being made a fool of and says, "Here, monkey, hop on my back so you can watch me chew that poodle to bits!"

Now, the poodle sees the leopard coming with the monkey on his back and thinks, "What am I going to do now?", but instead of running, the dog sits down with his back to his attackers, pretending he hasn't seen them yet, and waits until they get just close enough to hear. "Where's that damn monkey?" the poodle says, "I sent him off an hour ago to bring me another leopard!"

