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IN THIS ISSUE:

- The Able-Bodied Person (Page 1)*
- The Truth about Bottled Water (Page 3)*
- Alas, Poor Peasant (Page 4)*
- Neurons and Motor Units 101: (Page 5)*
- Orthotics Aid in Mobility (Page 7)*
- Nuclear Stress Test (Page 9)*
- Polio Survivor Registry (Page 10)*
- Travel Tips (Page 10)*
- Polio Trivia Facts (Page 12)*

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If you have articles you'd like to contribute, please contact me at the above email address

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If you have anything you would like posted concerning your local support group, please contact me.

The Able-Bodied Person

by Don Hansche, editor

Those of you who know me, know I'm not a polio survivor, but the husband and supporter of a polio survivor. I usually write my feelings since it's easier to get them out on paper. I have worked on this letter for several months. It started out as a letter I received via email. I did some editing to make it fit to my feelings and then printed it out and gave it to my wife. After she read it, she decided it would be great to add as an article to the newsletter for other polios to read; with the hope they will understand more also.

I don't mean to fill it with overbearing sentiment. Understanding is not an on/off switch. It seems to always be about raising awareness for people with whatever issue. And while raising awareness is great, there is always a flip side to the coin.

My perspective may be a little off, but it's not so much about being sick or healthy, disabled or able-bodied; it's more a matter of limitations. I know some of you deal with a mild case of PPS while others deal with all aspects of the disease. While it's the same disease, one lives a very normal, happy life while another is registered disabled and unable to do what others do.

There are people who view themselves as healthy (even though they have PPS or some other debilitating disease or disability), and others who can't. It seems to always be about people who are the exception. Dealing with a disability is not only about people without a disability treating people with disabilities with understanding, it's also about people who have a disability, some their entire lives, understanding people who aren't disabled, or the so-called able-bodied.

Most of the time, I think it's the able-bodied that needs to be a little more understanding and a little less demanding; but in reality, it's a two-way street. So, here's my letter, my thoughts, my feelings; Many of them, possibly the same as your spouse, family and/or supporter(s). But then again, maybe not.

Not being disabled doesn't mean I don't have the capacity to understand or listen. I'll never know exactly what it's like for you, but I try to understand when you explain things a little more. Our lives are very different and I know I make

assumptions about things I don't know about. These things are based on my reality, not yours. I mean well, even when I get the facts wrong.

I can't keep up with your rapid change of pace, mood and needs. I try to be accommodating by learning from past experiences. So when I am perplexed as to why you could walk yesterday and today you have issues sitting up, don't take it personally. My capacity doesn't change much. I can do pretty much the same things every day and it's difficult some days to understand you can't.

I get things wrong. I too, am only human. Some days, independence is important to you and helpful gestures are not acceptable. Other days you don't have the luxury of doing it yourself and when I then do not offer to help, you seem upset. I don't know what you need unless you tell me, as your needs can change on a minute to minute basis and it's not always obvious.

Getting out and doing things make me feel better. I don't suggest that it's the next miracle cure, but when you are bed-ridden or house-bound, I really do think that getting out can lift your spirits. And, while your illness may not be caused by depression, it's easier to see the light at the end of the tunnel when you're not disabled as well as depressed. I may suggest the wrong thing to do, but just sitting in the garden can lift my spirits when I've had a difficult day. So, I think it can do the same for you.

Most of the time when I say 'now', I really mean within a larger time frame. And sometimes, you do too. I don't know the difference between delaying for an hour to take one type of medication and needing to take another this very instance. I don't understand why some days you can stand up and wobble and when I say, "Sit down" you say, "I will, I just want to finish pouring my coffee", and on other days, one second you're standing and then you're asking for help back to your chair.

Life rarely gets critically urgent for me. It's not as if I'm going to die if I don't do a particular thing within the next few minutes. I forget, however, you could. I forget very small actions have massive complications for you and that you can't put it off even though you often want to. It's difficult to understand at times you can seem fine one minute and then immediately need to go rest. Usually, there is no time for you to explain and it leaves me somewhat in the dark.

I hate being ill. I am miserable when I have the flu or a cold and can't function properly. Being ill is not normal for me. I get grumpy, frustrated and have to adapt my life completely to accommodate it. I have responsibilities and commitments that I cannot tend to when I am not well and so getting better is a high priority for me. I'll happily try anything and everything on the off-chance that it may help, even just a little. I seem to always, instinctively, try to help you do the same.

When I make suggestions, I only have your best interests at heart. I know that you have an incurable condition, but maybe there is something somewhere that will make you feel better. I remember what a difference the heating pad made; and the electric blanket; and the warm socks I gave you for Christmas made. Every little bit helps and I know you don't always have the time and energy to look into things and, so, I do that and bring you things I come across on the off-chance you haven't tried it yet; hoping maybe it could make your life a little easier. It's hurtful when you don't even bother looking or listening.

I cannot feel or see your pain. I don't know how you are today unless I ask. I don't know what you can do today unless I ask. I don't know if you need my help today unless I ask. Don't get angry because I ask so many questions that make it seem as if I don't understand. I do my best with the information I have, but I usually need more.

I can't know everything about every health condition and disability. Disabilities and chronic illnesses come in so many shapes and sizes. I try to keep up by comparing the people I know who are affected. It's a small help as there seems to be more differences than similarities, but it's the only way I have to try and understand what your life is like.

I am not perfect. I have good days and bad days also. I have problems at work, financial worries, a full-time job, a family to take care of, even though they may not live with us; sick relatives to visit or worry about; and friendships can be quite time-consuming. I may not experience the pain that you have, but you haven't experienced the day I've just had. Being healthy does not solve all the world's problems and it certainly does not mean my life is easy.

I can't help it when I'm well. Don't look at me with envy when I put on my work jeans to go work in the yard, or resentment when I dash about the kitchen, singing along to the radio as I cook dinner. Please don't make me feel guilty for being able to do the things you can't do.

There are times when I'd rather stay home with you, instead of going fishing or visiting family like you ask me to do. I may not like TV or maybe the show you're watching, but if you record your show and turn the TV off, I will probably enjoy just sitting next to you, or chatting with you.

We are still the same people we were when we met. The only difference is we're both older, you're becoming more and more dependent on mechanisms which make your life easier and me to help you with these devices. We're in this together for the long haul. However, we need to work at it together; to understand one another more in depth; to understand it is reality and it's not going away. This, I CAN do; this, WE can do!

I hope I haven't offended anybody or caused trouble between any couples; but instead, have helped you to understand more, if you didn't already. Again, these are my feelings and I hope it will help more than hurt.

The Truth about Bottled Water

from Men's Health, by David Zinczenko

Imagine you've just been given a choice: You have to drink from one of two containers. One container is a cup from your own kitchen, and it contains a product that has passed strict state, federal and local guidelines for cleanliness and quality. Oh, and it's free. The second container comes from a manufacturing plant somewhere, and its contents — while seemingly identical to your first choice — has not been subjected to the same strict national and local standards. It costs approximately four times more than gasoline. These products both look and taste nearly identical.

Which do you choose?

If you chose beverage A, congratulations: You just saved yourself a whole lot of money, and, perhaps, even contaminants, too. But if you picked beverage B, then you'll be spending hundreds of unnecessary dollars on bottled water this year. Sure, bottled water is convenient, trendy, and may well be just as pure as what comes out of your tap. But it's hardly a smart investment for your pocketbook, your body or our planet. We decided to take a closer look at what's behind the pristine images and elegant -sounding names printed on those bottles.

You may actually be drinking tap water.

Case in point: Dasani, a Coca-Cola product. Despite its exotic-sounding name, Dasani is simply purified tap water that's had minerals added back in. For example, if your Dasani water was bottled at the Coca-Cola Bottling Company in Philadelphia, you're drinking Philly tap water. But it's not the only brand of water that relies on city pipes to provide its product. About 25 percent of all bottled water is taken from municipal water sources, including Pepsi's Aquafina.

Bottled water isn't always pure.

Scan the labels of the leading brands and you see variations on the words “pure” and “natural” and “pristine” over and over again. And when a Cornell University marketing class studied consumer perceptions of bottled water, they found that people thought it was cleaner, with fewer bacteria. But that may not actually be true. For example, in a 4-year review that included the testing of 1,000 bottles of water, the Natural Resources Defense Council—one the country’s most ardent environmental crusaders — found that “about 22 percent of the brands we tested contained, in at least one sample, chemical contaminants at levels above strict state health limits.”

It’s not clear where the plastic container ends and the drink begins.

Turns out, when certain plastics are heated at a high temperature, chemicals from the plastics may leach into container’s contents. So there’s been a flurry of speculation recently as to whether the amounts of these chemicals are actually harmful, and whether this is even a concern when it comes to water bottles — which aren’t likely to be placed in boiling water or even a microwave. While the jury is still out on realistic health ramifications, it seems that, yes, small amounts of chemicals from PE T water bottles such as antimony—a semi-metal that’s thought to be toxic in large doses — can accumulate the longer bottled water is stored in a hot environment; Which, of course, is probably a good reason to avoid storing bottled water in your garage for six months — or better yet, to just reach for tap instead.

Our country’s high demand for oil isn’t just due to long commutes.

Most water bottles are composed of a plastic called polyethylene terephthalate (PET). Now, to make PET, you need crude oil. Specifically, 17 million barrels of oil are used in the production of PET water bottles ever year, estimate University of Louisville scientists. No wonder the per -ounce cost of bottled water rivals that of gasoline. What’s more, 86 percent of 30 billion PET wa ter bottles sold annually are tossed in the trash, instead of being recycled, according to data from the Container Recycling Institute. That’s a lot of waste—waste that will outlive you, your children, and your children’s children. You see, PET bottles tak e 400 to 1000 years to degrade. Which begs the question: If our current rate of consumption continues, where will we put all of this discarded plastic?

Everyone is entitled to their own o pinion, but not their own facts.

Alas, Poor Peasant

by Millie Lill

It’s summer here in Saskatchewan and beautiful. In former days, I would look forward to family barbecues and picnics, but I don’t do that now. For one thing, the family is nearly a thousand miles away, so it makes a longish commute. For another thing, I have, in my old age, discovered the death of my Inner Peasant. Do you have one of those?

She’s the one who loves to camp, hike, cook over an open fire, chase children till they all drop in fatigue. I’m not sure my Inner Peasant hasn’t always been at least comatose, if not terminal, but I do remember her on the farm, lugging sacks of seed corn and beans, feeding cows and nursing ailing calves back to health, caring for children, feeding hired men. Now, as I look closely into my own eyes in the mirror, I see her withered hulk lying in a corner of my mind, obviously no longer in working condition.

These days, I am a PPS Princess. PPS Princesses do not have to work till they are exhausted and have no more usable motor neurons. Now we have People Who Do That. We don’t have to stagger behind a lawn mower, scrub floors or carry in groceries. Our People do that for us. I have a girl who takes care of my yard in summer and shovels snow in winter. I call Willow my Lawn Ornament/Snow Angel. Arlene comes in twice a month to shovel out the house; I mean do the heavy cleaning. I can also ask Arlene to drive me to my doctor’s appointments. My friend Kathy and I go shopping once a week and she helps me

carry in the results of the trip. Life is good for us PPS Princesses. Especially if you have a spouse who can pay for your People or one who is willing to, himself, be a People.

The problem is when I forget. Sometimes, my Inner Peasant stirs to life and tells me I can do this myself. And, of course, I can. It is difficult and I will pay dearly for it with debilitating fatigue, increased pain, and muscle spasms from You Know Where. But I can still do it. Then my Princess side gets into an argument with The Peasant and I get a bit down. Sometimes the Peasant wins, briefly, but in the end, I always come back to being a PPS Princess.

I think all of us with PPS are now Royalty. Let's try to remember that. It's so much easier to follow the Conserve to Preserve guidelines, if we just remember that Royalty does not have to do anything they don't enjoy. Let them eat cake!

Neurons and Motor Units 101:

by Annie Bassham

A Nerve cell, or Neuron, is comprised of the Neuron cell body-which has the nucleus inside it - at one end, the Axon (which is very thin, but it's really, really long - sometimes over a meter long, and at the other end of it is the Nerve Junction and the Neuro-Muscular Junction. (*Hmmmm. I had a little drawing of a "Neuron character in here but can't seem to bring him up!*)

How do Neurons talk to each other? They send out chemicals called Neurotransmitters across Synaptic Clefts (with little receptors in the ends of the each Neuron to take them in). These are usually just called Synapses.

One Neuron to another:

Neuron Maxine: "Hey Mack! You there?"

Neuron Billy Joe: "Mack's busy. Whaddaya want? I'm eating lunch!"

Maxine: "I want you to tell the legs to lift up high enough to clear this curb before they trip over them and cause us to fall on our face!"

Billy Joe: "YyyyOK. Will do."

And he passes along the message to the next Neuron in line, who passes it to the next, and so on. And amazingly enough, it gets there in time for the legs and feet to get it, and another disaster is diverted!

Now, a MOTOR UNIT is comprised of the Nerve cell (or Neuron), and all the muscle fibers that are attached to it. When the initial Polio struck, it damaged (or killed) a large percentage of the Neurons in the Brainstem, and also in the Anterior Horn cells of the spinal column.

Poor little fellas, those muscle fibers - they were suddenly orphaned. They no longer had a "brain" or Neuron to tell them what to do; Hence the paralysis. So they sat there, twiddling their thumbs and thinking, "Well, well, well, Wanda...., you never call... you never write." (Nobody told them that Wanda, their particular Neuron, died and would never write again. So sad... :-((But! Another Neuron, in time, would!! :-)))!

This went on for a long time right after the Poliovirus hit. Now, after the initial period of illness, (six months to a year or so, maybe longer for some folks) the neurons that were left but were damaged, sort of came back to life a bit.

But there weren't so many of them now. So the Neurons (ingenious little buggers) made a plan; they sprouted more terminals (entrance doors) at their "Neuro-Muscular Junctions" in order to have places for more Muscle fibers to plug into, and decided to go recruiting! They sent out signals (Neurotransmitters) to the orphaned fibers. Something like this:

Neuron Wendy: "Hey, Joe?"

Muscle Fiber Joe: "You talkin' to me?"

Wendy: Yep. Come on over to my place and plug in - it's the "happenin' place!"

Joe: "Well, sure. I'm not doing anything."

So he now attaches to the Neuro-Muscular junction; but not only him, so do lots of his buddies.

Now, a "Normal, (before Polio) thigh might have a thousand muscle fibers attached to one Neuron. Each eye might have ten (The more precise the movement, the less muscle fibers, and the smaller the motor unit-see?)

Of course, every case of Polio was different, but: when polio hit and destroyed as many as 60% (or possibly more!) of the Neurons we had, and stunned around as much as 30% of the ones left leaving only 10% to work with, there were many, many orphaned muscles which as a result, became paralysed.

Now, there are far fewer Neurons left, and each one adopted lots - LOTS of muscle fibers - way more than the original thousand it was supposed to have adopted. (This was happening when we began doing our intense Physical Therapy stages. (My PT went on until I was out of High School.) And when this happens, the motor units aren't small anymore - they've gotten really "Large" because of the large number of muscle fibers attached to each neuron. (So, when your Dr. does an EMG and says "It shows 'Large motor units'", that's what he means.)

Back to the beginning phase of the PT:

They (the Neurons and the Muscle fibers) begin to develop this slow dance - it's a bit awkward at first, because the neurons are still stressed and weakened, and the fibers they adopt are so used to sitting and twiddling their thumbs, they have forgotten how to interpret signals very well.

But it begins: Ralph and Joe - both muscle fibers, along with thousands of their buddies, end up dancing together to the tune (orders) that the "Wendy the Neuron" is singing.

Ralph: Hey, guys - GET OFF MY FEET!"

Joe: "Sorry! It's Wendy's fault. She's singing off key and it distracted me"

Rest of the muscle fibers: "Grumble, grumble - We're doing the best we can. Just "Stuff a sock in it!"

And so it goes. But eventually, the more physical Therapy we took, the more the dance became organized, and rhythmic, and things begin to work almost normally. For maybe 30 years? 40?

And since most of us are Type A personalities who worked so very hard to gain our abilities back and pass as normal; Did we give these weakened Neurons a break and say, "Well, buddy, I know you're weak and tired. I'll go easy on you; cut you some slack?"

Nope. Not on your life. We went into "full tilt boogie mode", for as long as we possibly could. No breaks for the weak. Then?

Enter Post-Polio Syndrome

The little Neurons have trudged on, year after year, still in a weakened state, sending impulses to many, many more fibers than they were meant to. The metabolic stress on each Neuron has become tremendous. And NOW? Poor little things, they begin to just wear out and die.

This is what happens when PPS hits. And when these stressed Neurons begin to die - they don't just abandon the normal amount of muscle fibers they were supposed to have had. Now a thigh abandons not a thousand, but maybe fifty, or sixty thousand muscle fibers. So every time we lose Neurons, there is a noticeable effect. (And the more we lose the more noticeable.)

Of course we're talking about the bulbar neurons and spinal cord Neurons here, so the breathing begins to

be ragged and the swallowing mechanism begins to forget the right sequence for swallowing when their neurons begin to die out.

Legs and arms don't work so well anymore, gait may become unsteady, we may begin to fall more, and we may need assistive devices to help get around. (Of course, being typical PPSers, we put that off as long as possible and stress our Neurons even more!)

New weaknesses, new fatigue, sometimes new pain - and not everyone has pain (I don't) begins to affect us. Sleep disorders may plague us and we don't get enough recuperative sleep, sometimes restless legs and other things disturb our sleep and we never reach the Delta and Rapid Eye Movement phase which gives us the most benefit.

And sometimes the muscles in the diaphragms are no longer working well because their neurons have died, so we don't get enough oxygen when we sleep. So the Dr. will prescribe a Bi-Pap for us. (And that can be a whole new battle in itself!)

And sometimes we go through the stages of grief, because we can no longer do the things we used to. (The stages of grief are:

SHOCK and DENIAL: "This isn't happening to me! I don't believe it!"

ANGER: Why would God let something like this happen to me?? I worked so hard to be able to live normally - How could He do this to me?!!"

BARGAINING: God, if you'll only give me my normal life back - I'll do anything!"

DEPRESSION AND GUILT: I'm so, so sad. Life won't ever be worth living again if I have to live like this." Or: "This is all my fault. I'm scum. I did it to myself."

ACCEPTANCE: "OK. So this is what I have to work with. How can I get through this and have the best life possible for me?" This is where we begin to heal emotionally, and we begin to smile again.

Anyhow, this is a short (sorry, I tried!) version of what happens in Polio and Post Polio to the Neurons and the Motor Units!

Laughter rises out of tragedy, when you need it the most, and rewards you for your courage .

Orthotics Aid in Mobility

by Daryl Clayton Kennedy

The scientific community has yet to single out a definitive reason for the onset of PPS. However one thing is crystal clear, there must be a solution for the life changing after effects of the original ghost like infection. I use the phrase "ghost like" to put into perspective the nature of the original infection. As you know, PPS is simply the unfortunate reality that many polio survivors face years after the polio virus. Many live for decades with little to no complication until... "WHAM" it hits - the slow deterioration of muscle growth and the negative ambulatory effect resulting from depleting strength.

Solving this dilemma can be approached in two different ways. First; by limiting your movement and dampening your day to day activities in such a way that you aren't aggravating nerves, which cause fatigue or taxing underdeveloped muscles. And second; by providing some sort of helpful compensation or support for your fatigued appendages!

Biomechanics in the Form of Orthotics is an Outstanding Option for those Who Qualify for It's Support

The term Orthotics comes from the Latin word 'ortho', which literally means "to straighten"! Many PPS patients have turned to this form of palliative ambulatory support in order to give themselves the much needed sustenance required to lift tension and stress off their inflicted lower extremities (Legs & Feet).

The specific type of support needed varies between individuals as each case is different. Some may suffer from more severe deterioration and may need additional support. Determining the degree of support and mechanical assistance is assessed by your health care physician and his or her support team. We could spend hours going over the different designs and concepts governing an individual's specific orthoses device; so instead of putting you to sleep... I'll simply go over the overall expectations of all these devices

No Matter How Sever or Mild Your Need for These Products May Be, You and All Needing Aid From Orthotics Need to Settle for No Less Than:

1. Device that supports your weight
2. Delivers your specific range of motion in conjunction with your body type
3. Supports your joints
4. And last but certainly not least... alleviates focused stress by delivering full range of motion!

The important factor with all orthoses devices is full range of motion. Although all aspects of the devices function are detrimental to its success and usefulness, full range of motion is its main goal. The fact that the device is supporting your weight is crucial but full range of motion will give you the MOBILITY, CONFIDENCE and FREEDOM that most take for granted.

How are All These Attributes Attained?

Back tracking and peering above at the 4 factors that govern a useful orthoses, you must understand how these qualities are attained.

First is the materials used in device construction. The first attribute mentioned is support your weight. In reality this is easy to do as there are many materials that can support the weight of any human body; the catch is these materials themselves tend to be heavy.

Just imagine you had a leg brace that supported your weight and gave you full range of motion. "Complete bliss" you may be thinking... now consider that in order to support your weight it need be constructed of steel or better yet iron. Well as you know steel and iron are two of the heaviest metals in the world, no scratch that, known universe... so it would be impractical for you to gallop around with a 75 pound leg or foot brace. That's why the use of lightweight alloys has contributed to the practical use of orthotic devices.

Now we have orthoses that are as strong as the Brooklyn Bridge yet as light as a feather.....O.K. maybe not that light or strong but you get the picture! As far as range of motion, which is second on the required list of attributes, the constant pursuit of excellence can be attributed to new and up and coming advancements in the engineering of orthoses design.

Man seems to leap forward every year by implementing fresh ideas and concepts. These very concepts and ideas are the driving force in providing you with hope, mobility and the opportunity to do the things you wish without worrying about injury or missing out on the everyday activities that we love so dearly!

Needles to say, leg braces are the most commonly crafted orthoses devices recommended and used by PPS patients. Again each person is different so braces are rarely interchangeable between patients which means these products are hand made and custom designed. Any of us living in the United States or any large capitalistic country know that this means you'll be digging deep into your pockets for this fix!

....Wait my friend; don't get disappointed as there is good news for all PPS patients. These sturdy tools of ambulatory perfection are not as expensive as one would think.

Depending on your insurance provider and policy guidelines you are more than likely covered and will either qualify for 100% coverage or at minimum, half! Now I know this is welcomed news with the

condition of health care in the US. I can't speak of coverage in other countries as I'm unclear of their policies.

When it comes to finding orthotics specialist - you should consider a Google search as I'm convinced that Google can provide you with a list of contacts that will surely lead you down the right path. You should also consult your therapist or physician before jumping into a relationship with an orthotics specialist.

I truly hope you stick around and view additional articles; as this site - PostPolioBransonGoers.com can provide you with a healthy dose of knowledge regarding events in the Post-Polio community.

See you next time,
Daryl Clayton Kennedy

About the Author: Daryl Clayton Kennedy is the editor of disabled-mobility-scooter.com which provides [mobility scooters](#), [electric wheelchairs](#) and [3 wheel scooters](#) for those needing ambulatory assistance. Daryl also contributes to blogs and other health related websites throughout the Net.

The information presented in this article is in no way meant to replace treatments or prognosis given by your primary care physician.

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Nuclear Stress Test

(Reprinted from the January, 2004 North Central Florida Post -Polio Support Group On-Line Newsletter)

Stress tests are done to evaluate if there is a compromise in the circulation to the heart. A stress test is of two general types:

1. A regular treadmill stress test, and
2. A nuclear stress test.

A regular stress test is not suitable for everyone. It is good when the baseline EKG is normal and the person is able to walk satisfactorily on a treadmill. It costs less but it is less reliable than a nuclear stress test.

A nuclear stress test involves using very low doses of radioactive tracers. Radioactive tracers are given both at rest and when a person is under stress. The stress can be induced by exercising on a treadmill or by using chemicals. The chemicals used usually are Adenosine and Dobutamine. Adenosine is not suitable for patients with conditions such as asthma. The radioactive tracers are given to the patient when he/she is under stress and the images obtained are compared with the images obtained at rest. The nuclear stress test gives a fairly good idea about the degree of perfusion to the heart and also the motion of the heart. It provides a fairly good idea (not 100%) of the need for further cardiac testing such as catheterization.

A stress test is usually indicated when there is a moderate probability that a person may have heart disease. It is usually done for patients with chest pain and shortness of breath.

It is important to watch one's waistline, to eat a healthy diet (low-saturated fat, low-carbohydrate, high-fiber, high-protein), to exercise daily to the best of one's ability and to refrain from smoking.

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Polio Survivor Registry

From Gladys Swensrud

The following was posted in IPPSO July news magazine for anyone interested:

The John P. Murtha Neuroscience and Pain Institute, a member of the Conemaugh Health System in Johnstown, Pennsylvania has recently noticed your involvement with Polio survivors. We are a non-profit organization that focuses our attention on the therapy, education, support, and research of chronically ill patients. Our goal is to retrieve information about each Polio survivor to compile a database including demographics, age, symptoms, and other traits common to Polio survivors. The survey only takes 5 -10 minutes and all personal information is regarded as confidential. There will only be further contact if the responder deems it acceptable. Each response broadens our Polio survivor registry, which leads to a better understanding of the disease. Please complete and submit the survey and forward to all possible participants and other support groups. Thank you for your time.

Register at <http://www.postpolio.conemaugh.org>

Everything is changing. People are taking comedians seriously and politicians as a joke.

Travel Tips

(The following was sent from Pat Grimes after attending the Post Polio Wellness Retreat. Thanks, Pat)

Planning

Plan ahead as much as possible - it's worth it. I'm a notoriously, last-minute type person, and even I have to admit that a bit of pre-planning can make an enormous difference.

Check and double-check EVERYTHING. Don't be afraid to ask clarifying questions, and to restate your needs in detail to be sure they are understood. Be specific and don't assume anything. Your definition of accessible is almost guaranteed to be different than that of the booking agent.

Don't be shy - this is not the time. If you think you know a better way, or if something feels wrong - speak up. Don't assume that the flight, hotel or cruise staffs know anything about assisting someone with a disability. Sometimes they do and you get fantastic service, but it's not a requirement for the job and I'd rather you were safe than sorry.

It's often worth getting the assistance of an organization that provides accessible tours. They will take care of all the details for you - and will be able to advocate on your behalf if necessary. This leaves you the luxury of relaxing and enjoying your vacation - the way it's meant to be.

Hotels

Call the hotel directly and speak with someone who has seen the rooms (management, housekeeping, whoever). Don't call the toll-free number for the whole chain - the booking agent there won't know anything about a specific hotel.

Ask specific questions and don't settle for vague answers. Many hotels have a sliding scale of 'accessible room'. Your definition of accessible won't be the same as theirs. You need to ask about roll-in showers, grab bars, availability of shower benches or raised toilet seats, door widths, etc. It's often helpful to identify exactly which room in the hotel will suit your needs. If you can get that room number written into your reservation, it can help dodge problems later on.

Make sure your accessible room is 'guaranteed' and not just 'requested'. If you can get this in writing, great. Get as many details as possible in writing - email is fine. Anything you can use as proof if a problem

arises. If you can prove it was the hotel's mistake, they will be much more helpful - upgrading your room, giving discounts, etc.

Once you arrive at the hotel, feel free to arrange the furniture in a way that works best for you. We often push the beds against the walls and request that housekeeping take away some of the extras (armchairs, side tables, etc). Don't be shy.

Flights

When booking your flight, be very specific about your needs. The airline should have you fill out a form for travelers with special needs. I find it helpful to place a follow up call to the airline confirming the details. They will need to know:

- type of wheelchair (manual or power)
- dimensions of your chair (height, width, length)
- weight of chair (with and without battery)
- type of battery (wet or dry cell)
- if you need to use the aisle chair to get to your seat

Although the airline has you fill out the forms, it is the airport staff who will be helping you transfer in and out of the plane and stowing your wheelchair. I like to call the airport special needs desk to let them know we're coming so that they are prepared.

Don't be shy - the airport staff is likely not going to be as good at transfers as you and your attendant. If you would prefer your attendant to help with the transfer - say no - insist if necessary.

Label your chair - label to the point where you think it's probably overkill. Put labels on places where it shouldn't be lifted; labels on brakes (with instructions on which way to pull to disengage the chair); labels on the battery to indicate what type it is (wet or dry cell); label your name and contact info, etc. I also prefer to remove anything removable (footplates, head rests, etc.) before the chair gets stowed. Baggage handlers are not the most gentle I've met and I have seen first hand the way they lift the chairs - it is often scary. Again - don't be shy - insist that you and your attendant show them where to disconnect the batteries. If they aren't sure, they will disconnect EVERYTHING. Some people suggest taking the battery right out and setting it on the seat of the chair.

Car Rental

Be very clear with the rental company about your needs. Many car rental agencies will offer accessible vans with enough advance notice. Provide the company with all of the dimensions of your chair so that they can get you a suitable vehicle.

Bring your accessible parking permit from home. Most places will recognize out of the country/province permits. Do NOT just assume that because your van is clearly fitted for a wheelchair that the parking authority won't ticket - they will!

Equipment Rental

There are many companies that offer rental equipment. Your hotel may be able to suggest a company, but you should also be able to find something in an internet search. There are companies that specialize in rentals to cruise boats.

Book your equipment a month in advance, and then call to confirm a week before, and again the day before you leave.

If you are renting a Hoyer lift, bring your sling from home. They are often not included in the rental; and even when they are, they are usually uncomfortable.

Scooters and wheelchairs can often be rented from the same companies. Some people find it easier to have these things waiting for them at the destination rather than bringing them on a flight.

If you are ordering rental equipment, be sure to let the hotel know you are expecting the delivery and find out whether it will be delivered to your room or to a concierge desk.

Accessible Taxis

Don't assume anything! You often find the best service in the places you least expect it. We had an easier time finding an accessible van in Grand Cayman than we have on many occasions in Toronto. Cozumel also has an impressive amount of accessible taxis.

When booking your cab, it's imperative that you specify your needs. If you are using a power chair, or will not be transferring out of your manual chair - state this clearly... and repeat it... and have them confirm it. There have been accounts of people who classify a car with enough trunk space to store a folded manual chair as accessible.

After you book your taxi, if it hasn't arrived at the time it should, don't hesitate to call again. Occasionally, taxi orders get lost - no sense in waiting around for a cab that isn't coming.

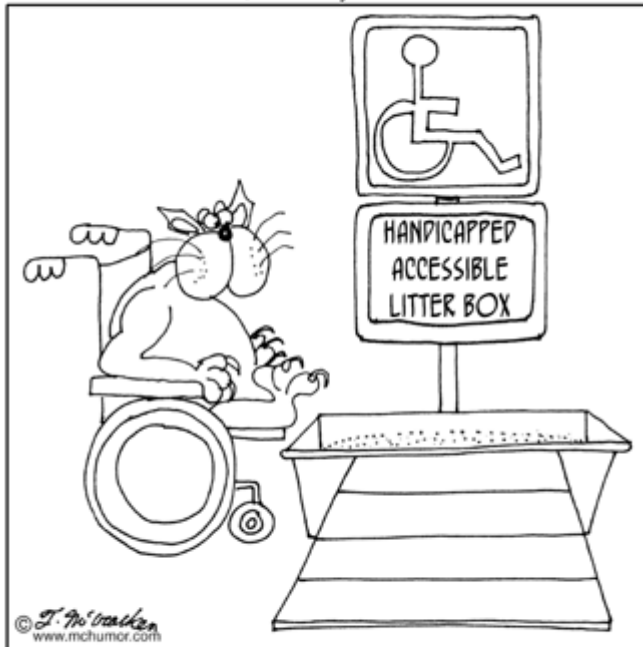
If you have great luck with a certain company, or specific driver, get their information (business card, etc.). You can always ask a taxi company to send a specific driver, and sometimes it's worth it for the difference in service you receive. You may also encounter a driver who is happy to give out their own cell phone number.

*These travel tips were handouts at the Post Polio Wellness Retreat, Apr 19-23, 2009
Camp Dream - Roosevelt Warm Springs Institute for Rehabilitation
Warm Springs, GA 31830
And were prepared by Sue Jones
Ontario March of Dimes/March of Dimes Canada
Stroke Recovery Canada/Polio Canada
Toronto, Ontario, Canada*

Polio Trivia Facts

Compiled from "Polio Trivia Facts" from PPASS, BC, Canada

- There are 1.6 million survivors of the Polio Epidemics.
- At least 78% of these survivors will suffer Post Polio Syndrome (PPS).
- A person who went from total paralysis to 100% normal strength has a high risk of developing PPS, while someone who went from total paralysis to 50% has a lower risk.
- Placing a pillow on your lap while typing or using a computer relieves the strain on your arms.
- Polio Survivors have a higher incidence of diabetes, allergies and digestive problems than the 'normal' population.
- 75% of Polio Survivors are 'non-visible'.
- One of the most difficult problems is finding a physician who is knowledgeable about Post Polio Syndrome.
- 'Use it or lose it' is a philosophy we must learn to ignore. Our watch words must be 'Conserve it to preserve it'.
- Common misdiagnoses of Post Polio Syndrome are ALR (Lou Gehrig's disease), Chronic Fatigue Syndrome and 'It's all in your head'.



We are all inclined to judge ourselves by our ideals; others, by their acts .

Answer to July Sudoku

2	6	8	1	7	5	4	3	9
4	5	3	6	9	2	1	8	7
7	1	9	8	4	3	6	2	5
6	8	2	7	1	9	3	5	4
5	4	1	3	2	8	9	7	6
3	9	7	5	6	4	2	1	8
9	7	4	2	5	1	8	6	3
1	3	6	9	8	7	5	4	2
8	2	5	4	3	6	7	9	1

August Sudoku

5				1			3	
	4							5
		6				2	8	
			6					4
		2	5	3	1	7		
9					8			
	1	5				3		
2							1	
	7			4				8

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