



# BransonGoers Gazette

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

## “Getting To Know You” featuring Randy (RB) & Annie Bassham



***What is your name and at what age did you contract polio?***

I contracted polio (the first time) when I was six months old. We lived in Trinidad - Dad was in the Navy - and the local island Doctor labeled it "Jungle Fever"...but as I got weaker and weaker and my legs refused to work at all, he sort of threw up his hands. His little nurse was also a navy nurse, and sought help from a Pediatrician she found herself dancing with at an Officer's Club dance. She asked him if he'd come the next day and see me, and he agreed. Within a couple of days the whole family was on a ship headed toward Portsmouth, VA to a Naval Hospital.

The second time was in 1955 - this one I remember - I had just turned four in March. We lived in Millington, TN. Mom and I were both ill on a Friday night - sore throats, stiff necks, high fevers, and I had been vomiting. I had stayed awake for a while trying to color - back then the cleaners who did Dad's uniforms would return his shirts on a piece of cardboard with pictures on it -perfect for coloring. I had finally given up, because I felt too bad to do it anymore.

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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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When Mom awakened the next morning, I was standing at her bedside asking for my crayons and scissors - I felt better and wanted to color again. She arose and found them for me --and then watched with horror as she realized that I couldn't use my right arm and that my shoulder was drooping. It just hung limp. Mom began screaming for Dad, who grabbed me up and immediately was on his way to the hospital with me. I had my teddy-bear in my left hand - the one I could use.

### ***Describe your early treatment for polio.***

#### The first time...

I don't know how long the ship took to get to Portsmouth. Mom said she spent most of the time hanging over the rails of the ship looking green. Dad and some of the ship crew took turns with me so she could go above for air. I do remember hearing stories about how the nurses and Dr's at the Hospital were so very sweet! I stayed there three to six months or so. (Every time Mom tells it she can't remember for sure!).

The nurses worked with me every day trying to encourage me to use my legs - to "crawl."

Instead, I "rolled." They would put down several blankets on the floor and one nurse would kneel at each end, taking turns beckoning to me to try to get me to come to them. [I rolled really well, I hear ;-)] When the doctor thought I'd made all the progress I could in the hospital (they didn't have a lot of kids and enjoyed taking care of me) they finally had to let me go. My legs were growing a little stronger. He sat down one day and took a pen and paper and drew out plans for what he wanted to send me home with.. A little wooden chair for me to sit in with material for a seat and openings cut out for my legs --which hung down and reached the floor, and the chair had wheels on it. (a child's walker, of sorts, but different). He hired (and paid for from his own pocket) someone to build it for me! Isn't that sweet?! My grand-dad came down and stayed with Mom and Dad for a while to help care for me --but instead of leaving me in the walker and letting me push myself with my feet, he carried me everywhere. Oh well, Grandpas, what can you say??!

#### The second time...

We arrived at the hospital in a big hurry! The first thing I remember was them getting me out of my pj's and putting me in a little white gown. I was in a good-sized room - empty, except for Teddy and me. It was inhabited only by us and a bunch of bunk beds.

The next thing was them doing a spinal tap - and speaking to each other in grim tones over my head. It scared me. Where was my Dad? And they had made me leave Teddy back in the room with all the bunks. I wanted him!

I don't remember a lot about what happened after that. They moved me into an isolation room, and overnight moved me downtown to Le Bonheur Children's Hospital in Memphis. I do remember the sweet smiles of the Nurses and Physical Therapists and Doctors. I had a room mate named Susan (I think) whose Mother stayed with us. They wouldn't let Mom stay. She did come up (every day that she could get a ride - she didn't drive and we only had one car) but she had to talk to me from outside a big glass window with a hole in it. She could, however, pass me candy bars and gum and always brought up puzzles and games (anything to try to encourage me to use my right arm) - that made everything sort of ok - though I missed her and Dad dreadfully. And someone else....

I don't remember at what point it was that I realized "Teddy" was no longer there. My faithful Teddy, who had been part of my life for what seemed forever, was no longer there. I don't think I realized that they had destroyed him until much later. I suppose he was contaminated. But one of my favorite nurses showed up with a package for me the day I was to go home. I ripped it open in typical child-like fashion - to discover a pink and black Panda bear with jingle bells on his tummy and eyes that opened and closed, and pink feet - he was instantly my best friend. I'll never forget that little nurse! (And I still have him - I named him "Cubby" - and he guards my jewelry box to this very day!

I went daily to the Naval Hospital to take Physical Therapy for over a year. We took a cab - had the same driver every day (the charge was a dollar a day). Sometimes they'd put me in the whirlpool tub and others I would work with all the little (and big) gadgets they had me work with. I remember the big wheel on the wall they wanted me to push forward and backward. (I probably remember that one because it was the hardest.) When I was thoroughly exhausted, it was time to go home.

On Valentine's Day, as Mom handed the driver his usual dollar, he turned and handed it to me, saying, "Here, sweetheart - Happy Valentine's Day!! Go buy yourself the biggest box of candy this will buy!" And I did!

I remember, too, the trip downtown to Campbell Clinic to be fitted with my shoulder brace; and after picking it up, fighting with my Mom while she tried to put it on me. It had a gazillion clamps, I think, and took forever every day! I hated it. I wore it for several years to correct my sagging shoulder. I threatened every day to lose it on the way home from school (but how do you say "oh, it must have slipped off somewhere" when the thing took an hour and a half to put on me?? I had the nerve to do a lot of things, but not quite enough to lose the dreaded brace!

I took Physical Therapy off and on, up until the year I graduated from High School. I think I decided that summer I was a senior that was going to be it.

### ***How did polio affect your teenage years?***

Teenage years? I only remember a few things that made an impression on me.

One - I was determined to try out for cheerleading in the seventh and eighth grades! I worked like a Trojan through the summers and in the P.E. classes during the years at tumbling, determined that I would be able to learn to do cartwheels (because even then, tumbling was a big thing in cheerleading). But try as I might, I couldn't do it. I had trouble with the kicks --my legs just weren't strong enough--and the cartwheels were just beyond me. Each time I landed on my head, I'd sit there a moment trying to gain my bearings, and silently cursing my weak arm for not holding me up. My P.E. teacher kept saying "Honey, I admire your determination, but you're going to end up with brain-damage if you land on your head one more time!!"

Finally, though I wasn't one to give up easily, I did. By the end of the eighth grade, I decided I would be a science-fiction writer.

I must say, that my legs and my arm didn't stop me from being able to do most of what I wanted. I rode bikes (the big thing was to get to the top of the hill and ride down --I could go almost all the way around the circle our street was on if I got a good start. I managed to dance under the streetlights and climb (carefully, I might add). I learned to swim, even if it was a little awkwardly.

Two - I think the only other thing that really did bother me was the fact that even in my teenage years, my shoulder did continue to sag a bit. I was really conscious of the way that sleeveless dresses and clothes hung on me. I was a skinny kid anyway, and worried a lot about my right shoulder. I don't remember sharing that with anyone, however. I remember when I began to grow up a little more and shoulder pads were invented. Hooray!!!

### ***How did this affect the way people treated you in school?***

I managed. Most of the time I was able to "pass" with the others. When I couldn't, the kids seemed to understand, and made allowances for me. I grew up with a great bunch of kids. If I wasn't able to do something it wasn't because I didn't try.

### ***How did polio impact your self-esteem?***

I'm not sure that it did, at all... If anything, I think that the Polio probably made me who I am, and I've never been sorry I had it.

### ***What was your occupation?***

I became a nurse. I think probably that's what I wanted to do because I remembered all the kindnesses given to me over the years by nursing and hospital personnel. I did nursing for around thirty years. Starting out as a nurse's aide for a couple of years, I finally went on the Nursing school and loved it! I did all different types, ER, surgical, OB, Med-Surge, Geriatric, Office Nursing (it seemed that each thing I did was my favorite). Oh, and finally Utilization Review (which turned out to be my least favorite) -- that's where I gathered info from the patient's chart and had to make my case before the Insurance Companies to try to get the patient's stay covered or get them more time. That was probably my least favorite type of nursing, even though I learned a lot. But it was the easiest on my body, which was being affected by PPS at the time.

### ***Do you have Post-Polio Syndrome (PPS)? If so, when were you diagnosed?***

In 1995, I began having trouble with my right arm again. I visited a Neurologist who did an EMG and told me he thought I might have PPS. He suggested that I go and see a specialist --and gave me some info on where to get a Videotape (produced in Canada --it was extremely informative and helped so much!) And he gave me a list of names of Physicians who specialized in PPS. I'll be forever grateful to him.

### ***Do you use any mobility aids? If so, how do you feel about using them?***

It's funny. Other than the shoulder brace that I wore (and hated) as a kid, I never had to wear or use any mobility aids. After I was diagnosed with PPS in '95 Dr. Wice suggested that I begin using a scooter to help me with work since the hospital was large and I covered many long hallways in the mornings (though the afternoons were spent at my desk most of the time). I was stubborn. I didn't want to use it so I put it off. I would certainly have been better off if I'd been compliant and used one, however. By the time I came home from work, I hit the bed, most of the time not waking up for supper. He was very helpful in writing a letter to my Hospital Administrator and asking him to let me job-share so that I could cut my working days to around three a week. (I about fell over when the Administrator agreed! Wow!) Over the next few years I progressed a little, but was forced to gradually cut my days to two a week, then one...

I even took up Photography to start my own business so that I could work my shoots around my rest schedules. It worked--for about the first six months, but the business grew rapidly and there were more and more shoots and less and less rest. I noticed that I became increasingly more tired and that I began falling frequently. In five years I broke four bones (because my feet were dropping and I was tripping over things). My last break was on Christmas Day, 2003. (ever broken something and needed to see an Orthopedic surgeon over the Christmas or New Year Holiday? Mercy!) It was a bad break that required months of physical therapy--after the cast finally came off I had lost the muscle tone and each time I tried to walk I fell on my face. Took me forever to be mobile again. The crutches I couldn't do --Rb kept trying to explain to the Dr. that my polio and PPS had left me with very little upper body strength (I don't think he ever understood that).

My business didn't stop for illness or bone breaks... That was also the year my daughter got married. By the fall of 2004 I had to give up weddings. Since I was my only employee --I just had an Assistant that helped me with weddings--I found myself so busy with Senior Pictures that I was working 14-16 hour days. I knew I was over-extending myself to the max. I kept hearing Dr. Wice's voice in the back of my mind saying, "Pace yourself--Pace, pace, pace!" I would stumble down the hill to the house late at night after one of those days thinking..."What am I doing?!!!"

In November everything just stopped. My ability to sleep stopped, my ability to breathe when I lay flat stopped. I suddenly developed Reflux Disease (but I didn't know that's what it was then). My short-term memory was suddenly terrible. My regular Dr. didn't listen to me --I know he thought I was just having anxiety attacks--he offered me Ativan, which I politely refused. He sent me to a local Pulmonologist, who thought I had everything from Wegner's Granulomatosis to Sarcoidosis -- he ran a barrage of tests. All negative except the Sleep study which showed I was getting 0.0 REM sleep ; and had tons of Alpha-Wave

Intrusions. I'd start to try to get to sleep and suddenly I'd be jerked wide awake (this happened hundreds of times a night and after happening ten or fifteen times in a row I just couldn't make it back to sleep the rest of the night). I finally decided the pulmonologist was grasping at straws, and when I ran out of my Advair inhaler between Christmas and New Year he was nowhere to be found. ("Yes, he was there", his office assured me, "he just wouldn't be returning phone calls this week, call back after the first of the year...")

My next call was to Dr. Wice. I'd not seen him in a while. When I did, I was amazed at how quickly answers came. He had me see a new Pulmonologist (Dr. Oscar Schwartz --he was absolutely great!) and a GERD specialist--also great! Ran another sleep study on me within a week or so because we couldn't get records from the first pulmonologist and began treating my sleep disorders immediately. Ran MRI's to make sure there wasn't anything else going on and a ton of lab tests to rule out lupus, scleroderma, you name it. I was no longer able to work. I fulfilled my last obligation for the Highway Patrol Christmas Party and that was the last thing I was able to do.

Long story short — [too late?? ;-)] I spent eight months sitting up in a chaise lounge to sleep. In the summer hubby bought me a bed that the head elevates on --I still can't lie flat but I sleep wonderfully. My sleep disorder was finally being treated responsibly and I was making progress. In June Dr. Wice told me I was walking with foot-drop and that's what had been causing my falls - they fitted me with AFO's for both legs with springs in them that help me lift my foot after taking a step. In July they fitted me for a power chair and though I didn't need to use it "all" the time, I did use it a lot. Last year - 2007, I began using a cane to help with balance. This year I bought a walker called a "rollator" that helps me with long distances, has "bicycle brakes" on it and a comfy seat if I get tired.

Do I resent having to use them? Not at all. I'm just thankful to be able to be mobile. Whatever ends I need to do that are ok. I'm not ready to hang it up yet! I want to go places --we love to travel! The braces aren't my favorite thing to wear -- I have to use shoes that are two sizes larger than my feet to accommodate the braces (thus, the end of 'cute shoes' for me.) But - have I fallen and broken anything since getting them? Nope! I no longer have to sit home and look at the walls closing in. This year we got a lift that fits in the van and I can even go shopping again -- by myself, if I want to! (I tell you, I was having real mall withdrawal!)

### ***What are your interest, hobbies?***

Oh, lots! Cross-stitching, (RB says I've had lots of practice at being "cross"), playing the piano, (I also have a flute and a tin-whistle), I still do photography, but it's what I "like" doing now instead of having to meet deadlines... traveling, though I don't do as much since my folks are ill, reading murder mysteries, pottery, and woodcarving - oh yeah! I also love Theatre, but haven't been able to do it for several years.

### ***How does PPS affect your way of life?***

It definitely slows me down. After a week of being at my folks' house every day all day long and running them back and forth to their doctor's office visits and taking them shopping. I'm often too tired to do things I enjoy.. I signed up for a stained glass class three weeks ago and haven't made it to class once - I finally called the teacher this week and apologized profusely and bowed out of the class - I probably shouldn't have signed up in the first place. It's still hard for me to "pace" - and I know better. But I'm the only kid here and it falls to me to help them.

### ***What message would you give to someone newly diagnosed with PPS?***

Hmmm, oh my! Don't do what I did! Listen to your Doc and DO the pacing! Rest when you're tired! I think if I'd been smart and had not pushed myself to the top of my limits for so long I'd be in much better shape than I am now. I'd be stronger and able to get around better. I feel like I did a lot of this to myself by refusing to pace.

### ***Are you married, and if so, how did you meet your mate?***

RB and I have been married for 37 years this year.. He 's just been the most wonderful man! He's been extremely supportive and kind and loving, from the very beginning. Once, on the way home from seeing Dr. Schwartz who had spent an hour and a half with a nursing student showing her where I was missing muscle mass and how weak my diaphragm muscles were, and so on, and so on. RB said quietly, "I apologize so much. I never realized how hard you've been working all these years to compromise for the weaknesses you have. I just never realized....."

### ***Any comments to or from your spouse/supporter?***

Yes, and I think all of us do this from time to time. I find myself being frustrated at my lack of ability to do things and taking it out on him. He's good to me - very much so. He tries to keep an eye on me and meet my needs before I have them. But he's human, and he forgets things at times.

For instance... perhaps I'll find that it's hard to get out of the car because it could be closer to (or farther away from) the curb. And I fuss about it before thinking. Or, he'll get out of the car to go into the house and leave several things that need to be taken in for me to manage. With a cane in one hand it only leaves me one other hand to manage carrying a bunch of stuff. If I think before getting frustrated, I can simply say, "Honey, can you carry some stuff for me?" And of course he doesn't mind at all.

Often if I start to fuss he'll say, "All you had to do is ask for help," and I realize that in my typical former polio days, I deliberately resist asking for help - I just try to do it myself. But that causes friction at times.

Or maybe it's just that I don't feel well and am frustrated by that and I just find myself taking my frustration out on him. If I would stop before I think, I'd realize that he is the one who is there for me. He's the one who helps me get Mom and Dad to the doctor on days when I don't feel well. He's the one whom I can and do depend on. And he's always there. How can I be ugly to him? I try very, very hard not to be, but that's one of the things I have to work the hardest on. We need to remember that life is tough for supporters too.

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## **From the Editor:**

*By Don Hansche*

### ***June Newsletter:***

As many of you may have found out by now, there was no June edition of the BransonGoers Gaze tte. Why? Well, we were still wrapping up the reunion on June 2. We then drove to Terre Haute, IN where we stopped to rest for the night. We finally arrived in Erie, PA, where we met our youngest son, Jeremy, and his fiancé, Alexis. They were married on June 6 in Erie.

We left Erie, PA on June 8 for our journey back home. We stopped to stay overnight with Margie and Jim in Akron, OH. The next morning, we continued from Akron to Jackson, TN, where we again stopped to rest overnight. Next morning, we were back on the road. We stayed a couple days with my mother and family in LA before finally getting back home June 13. We had a terrific, but exhausting time.

We regret not having the chance to list our June birthdates and anniversaries due to the lack of a newsletter. I have listed them at the back of this edition. Please take a moment to give those folks a 'Happy Belated' birthday or anniversary.

### New Members:

During the month of June, we have added 7 new members to our ever -growing group. Please welcome our new members: Lorna Johannes, who incidentally made it to the 2008 reunion, Jaki Browne, Jeanne Houghton, Don Pharr, Mike Cook, Sarah Walter and last, but not least, Patti Loquasto.

### A Family Affair:

As I search and research for interesting polio and post-polio articles, I came across the one called "A Family Affair" and thought it needed to be here for the benefit of all supporters, especially the spouse. Sharon (my wife and survivor, for those of who may not know) and I have talked about this and, although it is hard for me to accept, she really doesn't resent the fact that I have things I like to do, whether she's up to it or not. I feel guilty as I'm sure you do also. But get out anyway. Your polio spouse really doesn't mind. It gives them time to rest and recoup without feeling guilty for lying around while your there.)

### For passengers flying with oxygen:

For those who may not know already, a new ruling on May 13 by the Department of Transportation shifts the burden of electromagnetic interference testing to the device manufacturer. Also, passengers using oxygen devices will not be required to have attendant assistance, and they will be able to use their devices during all phases of a flight. Devices must be tested and meet FAA requirements, and all airlines will be required to allow travelers using ventilators, respirators, CPAP machines and portable oxygen concentrators to be carried on board, stowed or used during flight. (For more details, visit [airconsumer.ost.dot.gov/rules](http://airconsumer.ost.dot.gov/rules).)

This rule came from an amendment to the 1986 Air Carrier Access Act with regard to "nondiscrimination on the basis of disability in air travel." It will go into effect May 13, 2009 and adds accommodations for travelers who use oxygen and other respiratory assistive devices.

Airlines previously contended that testing oxygen devices to determine electromagnetic interference as well as allowing use of such devices during ascent and descent on short flights, was burdensome to attendants and cost-prohibitive.

### Fake Virus offers Safer Vaccines:

According to U.S. researchers in an interview with Maggie Fox, Health & Science Editor Washington (Reuters), an artificial virus was created to protect mice against the polio virus. The first synthetic version of the polio virus was created in 2002 at the State University of New York, Stony Brook.

Reporting in the journal Science, the mice survived what should have been a deadly dose of the polio virus after being vaccinated with the fake vaccine.

Although the synthetic virus(es) is far from suitable for human usage, there is "A lot of potential for this approach." according to Butch Futcher, a professor who worked on the study. The fake virus will not cause disease unless given in high doses.

Present polio vaccines have virtually eradicated the disease in most countries. But an oral vaccine that uses a weakened version of a live polio virus can sometimes get back into the water supply and mutate into a form that can infect people. Dr. Jonas Salk's original polio vaccine, which effectively rid the United States of the feared virus in the 1950s and 1960s, used a "killed" polio virus but had to be injected. Doctors have been looking for a safer, yet effective polio vaccine that is as easy to administer as the drops.

According to statements from the research team, the fake vaccine can never mutate back to the wild type because of the number of 'cuts' in the original polio virus. They also stated it is possible other diseases can also be treated using synthetic vaccines made from the original virus(es) through "hundreds of changes to sufficiently cripple the virus by using the 'death by a thousand cuts' approach."

# The Dignity of the Disabled

by Henry Holland

Several weeks ago, a local theologian and educator was the guest preacher in my church. He is an orator and an excellent speaker. During the processional hymn, in which the choir and clergy walk slowly down the long center aisle of my church, this preacher was robed appropriately but was walking unsteadily with a cane. To climb the three steps to our chancel, he secured his balance by holding on to the side of the pulpit. Later in the service he held on to the ornate polished wooden railings in climbing the six or eight steps to the pulpit. Once in the pulpit, he seemed very secure as he had a large podium on which to lean. Multiple Sclerosis is his personal adversary. Perhaps others in the congregation were not as keenly focused on these little triumphs of his physically moving from the reception area of our church sanctuary to the pulpit. I was aware of his little triumphs because I deal with similar “little triumphs” every day. Many of you probably share the same feeling or experience. This preacher could have elected to enter the chancel of my church from the side and avoided the whole processional. He chose not to do that. How often do we choose not to do something just because it might be easier? We probably do this more frequently than we realize. One of my lasting perceptions of this preacher’s physical pilgrimage to the pulpit was that the whole experience evoked indescribable dignity.

How often do the disabled and particularly polio survivors live their lives with dignity while daily achieving little triumphs? I suspect that we don’t talk or give much thought to this concept of dignity. Among those who attend our support group meetings, I often observe this dignity among our members. Most of us are unaware that this dignity may exist.

President Franklin Roosevelt communicated dignity in his public life despite his efforts to hide his disability. Historically, it is sometimes difficult to find details of how FDR moved from one place to another when he was exposed to public view. One such example occurred in August 1941 during his summit meeting with Winston Churchill at sea off the coast of Newfoundland. This was a secret and highly classified meeting that occurred just four months before the USA entered World War II. On Sunday, August 10, a combined worship service was held on the English ship *Prince of Wales*.<sup>\*</sup> The initial meetings of this first summit had been held on the USS *Augusta*, which was FDR’s ship of travel. FDR was present for the worship service, which had been organized by Churchill. How did he get from the USS *Augusta* to the *Prince of Wales*? I found some description in a book by Theodore A Wilson.

“The leading destroyer, USS *McDougal*, her bow level with the *Augusta*’s main deck and *Prince of Wales*’s stern carried Roosevelt to the great British warship. The president was hatless and wore a blue double-breasted suit. Holding a cane in his right hand and aided by Elliott (his son) on his left, he crossed a narrow gangway from *Augusta* to the destroyer, there to receive the salute of a Marine honor guard and band. *McDougal* then made a “Chinese landing” (bow to stern) on *Prince of Wales*. FDR walked slowly along a starboard gangway to the deck, where he was received aboard with full honors. Fifteen hundred or so men, including approximately 250 United States sailors and Marines, stood at rigid attention for the two national anthems. Roosevelt moved the length of the ship to his place of honor on the quarterdeck. The prime minister, dressed in the uniform of the Royal Yacht Squadron, watched stolidly, although he may have been as surprised and moved by this display of determination as were several of his aides. Captain Yool recalled that “many of us in England had thought that the President was unable to walk at all....One got the impression of great courage and strength of character as he slowly approached the assembled company. It was obvious to everybody that he was making a tremendous effort and that he was determined to walk along that deck even if it killed him.” This may have been the longest walk FDR had attempted since being stricken with polio.”

Certainly this moment displayed the dignity of a disabled President and Commander -in- chief. Many of those who witnessed this event would perish when the *Prince of Wales* was attacked and sunk in the Pacific four months later.

Many of us may be unconscious of our own dignity in living with a nearly life long disability. Whether it be walking or rolling across a room or sidewalk, climbing a few steps, getting our of a chair and trying to stand, or just trying to communicate, we may all go about these simple activities with a quiet and unpretentious dignity. With the new realities of Post -Polio Syndrome, even greater challenges and a higher dignity surround us.

*References: The First Summit by Theodore A. Wilson, University Press of Kansas, 1991, Pages: 97 -98*

\*Note: The scripture verses that Churchill selected for the worship service were Joshua 1:1-9. Churchill chose these verses with Roosevelt in mind.

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28th January 1997*

Dr Henry Holland is a qualified medical officer and furthered his education to become a psychiatrist and has been a great contributor to the PPS world for many years. We thank him for giving us permission to print his articles to the benefit of our members and the public.

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## ***Is there another word for synonym?***

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### **A Family Affair**

*by Dr. Adam Gruszczynski*

One of the difficulties of being in a relationship with a person who has a chronic illness is the belief that we are alone. Everything is directed toward the person with the chronic illness and while that is fair enough, it is important to remember that the partner is also having to make adjustments to the illness.

In today's discussion I am going to outline my situation when my partner, Dr. Mavis Matheson, began having problems with post-polio, and how we managed our relationship as her post -polio progressed.

Mavis and I met in Regina as interns in 1985. Early in our relationship she mentioned she had had polio and had recovered. She led an active life, had swum competitively and enjoyed hiking and skiing -all the things that I enjoy doing. She hadn't yet heard of post -polio syndrome, so it never occurred to her that she might experience problems in the future.

We had two children and worked together at the same clinic for five years. We were traveling and enjoying life together-things were working pretty well. She was one of those active, Type A people-always doing five things at the same time.

In 1991 we decided to form a clinic of our own. This required a lot of organizing and Mavis did all of the detail work. She was finding herself increasingly tired, needing to sleep more and becoming irritable. I was also becoming irritable and we found ourselves pulling away from each other. We thought the changes in our relationship were due to the stress of setting up the clinic and expected things to right themselves when we opened. Things did settle down. We shared the practice, I was working 3 days a week and Mavis worked 2-1/2 days a week. This gave us more time with each other and the children.

In early 1993, I found Mavis becoming emotionally distant. She was tired, going to bed more frequently and having more aches and pains. She was limping more and found herself spending the weekends recovering from the work week. Over the spring her symptoms got worse. Mavis began reading about post-polio syndrome and quickly realized that what she was reading was describing what she was experiencing. Her family doctor was not helpful as she had no familiarity with post-polio.

Mavis knew she had to start making some changes in her life. She cut out a half hour from each work day and, rather than running to work, started using her car. She found that she was ending the day in better spirits but was uncertain whether she was going to be able to get going the next day.

Things came to a head in 1993 when I got a call from the receptionist at the clinic saying that Mavis was taking medications from the drug cupboard. I cursed myself for not realizing that things were getting so bad. I was in denial and not paying enough attention to the realities of Mavis' illness.

We reorganized our responsibilities at the clinic, Mavis took some time off and I began to work full time. She did a time/energy study while she was at home and found that she was taking over 300 steps a day -while she was trying to cut down and rest. We lived in a four level split with the bathroom on one level and the kitchen on another. I realized that we needed to move to a one level home.

During one short month we went from having an equal relationship working together, to Mavis not working, me working full time and the family having to change our home. We also had to try to explain what was happening to the children who were 3 and 6 at the time.

As time went on, Mavis found that she was able to do less. She was not recovering and was becoming increasingly fatigued, even with her modified schedule. She began to get more depressed. I was becoming stressed and irritable as well and did not know what to do to make things better. I found myself staying up later and letting myself get more fatigued, thinking -if she's tired, I should be tired too. It's not very rational but when people are under stress they're not always rational.

Eventually Mavis insisted that I seek counseling. This was useful because when I was growing up my mother suffered from severe depression. It was like living with a chronic illness. There were times when I would come home and not know what situation I would be facing. When I left home I figured I had left the chronic illness and not have to deal with it again. Now here I was in the same situation only it wasn't going to be a couple of years and I would be able to leave. That was very hard to deal with.

Our situation continued to deteriorate throughout the fall and just before Christmas Mavis went into the hospital because of other health concerns perhaps ALS or Multiple Sclerosis. She was in the hospital for a week and had all the tests done. The doctors said "this is just a psychosomatic thing". By that time I had read enough, knew enough and observed Mavis enough to know that this was not the case. Mavis was depressed and I had to support her through that psychosomatic nonsense.

In January I started to keep a journal of my feelings, especially the feelings you don't want to share with your spouse. You don't want to tell them that you are tired of dealing with the problems; that you are tired of not being able to do things, and you are angry at them. It's not their fault but those feelings are still there and the journal provided an important outlet.

Mavis went to see Dr. Rubin Feldman in Edmonton. He did a few simple tests and diagnosed her as a classic case of PPS. He counseled her about changes she would need to make to maintain her health. She learned that many of the lifestyle changes we had gone through already were the things that she needed.

While she was in Edmonton I continued my journal, exploring my goals and values. I realized that the things that I found important in my life were still available to me in our relationship. It was important to me to have challenges, to grow personally and to have satisfaction. Our relationship provided a situation where I could have all of this. I didn't have to run away to be fulfilled.

It was also at this time that I realized one of the things Mavis was working through was the fear that she was going to be abandoned, that I was going to leave her. I found that the reason I wasn't running away was that I was meeting my needs in the relationship. The realization that Mavis felt that I might run away gave me a chance to show my commitment to the relationship. We hadn't married yet and I thought this was an appropriate time to propose to her. This was an important step in her realization that I was not going to leave the relationship.

Things were still unsettled though and we both needed a lot of separate time. Mavis needed time to come to terms with herself and to develop ways to rest and get her energy back. I needed time for myself to come to terms with what was happening with her, to grieve through the losses and to get comfortable with our recent changes.

In May 1994 things came to a head. Mavis got so tired and so distressed that she checked herself into the hospital. While in the hospital, she developed a routine of sleeping in the afternoons and resting and she felt much better. It was at this time I realized that either this relationship is going to work or it's not. Interestingly enough, while Mavis was in the hospital she had come to the same conclusion. We started settling into the routines of a more regular relationship. We discovered that there were ways of traveling with a disability. We discovered there are ways to conserve energy. We got a housekeeper. We found through trial and error that we were able to build our relationship again. We realized that we had some losses but there were new challenges that keep it worthwhile and exciting.

I have read many books about family relationships and chronic illness and through them have learned some very good advice. Be aware of your attitudes about chronic illness. If you have had previous exposure to chronic illness, there may have been some very positive or really negative events which could color your perception and your relationship. My previous exposure had been a very negative experience and I assumed that the current situation would be negative as well.

It is useful to be in the present and not dwell on what might happen tomorrow or grieve about things that have changed. Instead, concentrate on what is happening today. Worry about tomorrow, tomorrow. Getting worked up about things that might happen is a big waste of energy. Know your values and goals and be honest with yourself.

Take ownership. Acknowledge the situation and acknowledge that you want to be in the relationship.

It is also important to maintain boundaries and give yourself some separation. I live with an illness but it is not my illness. I am affected by it but I don't have to suffer from it. I can do things that I enjoy doing without having to feel guilty that my spouse is not able to do them. This separation gives me the energy to come home and do things together and deal with the stressful parts of the relationship when they arise.

All of these things are factors in taking care of yourself and your relationship. If you don't take care of yourself, you probably won't be helpful to your spouse. Sometimes you might need to acknowledge that at least things aren't getting worse and might even improve. Occasionally Mavis and I find there is another loss we did not expect. We find ways to adapt and get around the hurdle. We have found that our relationship is working because we've been through this challenge together. We each had to work on separate parts and were able to use the things that we learned to work together.

*Reprinted from the Saskatchewan Awareness of Post Polio Society Inc. Issue #29 March 1999*

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***Everyone has a photographic memory; it's just that some of us are out of film.***

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# Low Cholesterol Problems Arise

by Joe Graedon and Teresa Graedon, PH.D.

What may be good for the heart could be bad for the brain. Lowering cholesterol, especially bad LDL cholesterol, appears to reduce the risk of heart attacks. But new studies suggest that very low cholesterol might pose unexpected problems for the nervous system.

Researchers have analyzed data from a long-term study of Japanese-American men in Honolulu. Blood samples of healthy men were measured in the early 1990s. During the next decade, researchers noted who was diagnosed with Parkinson's disease. Those with low LDL cholesterol initially were significantly more likely to develop this neurological disorder (Movement Disorders online, March 31, 2008).

This is not the first time that low LDL cholesterol has been linked with a higher risk of Parkinson's disease. Other neurological problems also may be associated with low cholesterol. One study uncovered a link between low cholesterol and Alzheimer's disease (Neurology, Aug. 11, 1999).

Scientists in New Zealand have been monitoring adverse effects of cholesterol-lowering medications. They have noted that statins may be associated with depression, memory loss, confusion and aggressive behavior (Drug Safety, March 2007). The authors point out that "Cholesterol is crucial to brain functioning."

A new study (Neurology, March 25, 2008) links low LDL cholesterol to worsening of ALS (Lou Gehrig's disease). In fact, the researchers conclude: "The beneficial effect of hyperlipidemia (high cholesterol) on survival of more than 12 months is, to our knowledge, one of the most important documented."

Probably the most controversial issue hinges on whether lowering cholesterol with statin-type medications is linked to ALS-like syndrome. The French researcher who conducted the study on LDL and ALS, Vincent Meininger, M.D., Ph.D., was asked in a Neurology journal podcast whether there could really be a statin-related ALS connection. He responded, "I think yes."

It is very difficult for scientists to determine whether statin-type medicines trigger or worsen ALS. Many people have reported their experiences to [www.peoplespharmacy.com](http://www.peoplespharmacy.com) (analyzed in Drug Safety, February 2008).

Here is one example:

"My husband took Lipitor for several years. After a knee replacement, his leg muscle deteriorated, and no amount of exercise could bring it back. Then he developed swallowing problems. He had trouble breathing, but at the emergency room they found nothing wrong.

"He had a lot of pain and no relief even with pain medicine. His muscles weakened so much that he could not eat food unless it was put in a blender. He went from 165 to 113 pounds, losing so much muscle that he fell many times and could only walk with a walker.

"He was an active man before all this happened and exercised every day. He had so many tests to find his problem, but it was not diagnosed as ALS until the morning of the day he died in July 2007. This is a horrible disease and a horrible way to die."

No one knows whether there truly is a relationship between statin-type cholesterol-lowering medicine and ALS-like syndrome. The Food and Drug Administration is investigating this issue. Anyone who would like to report serious problems with such medications can do so at the Food and Drug Administration's web site: ([www.fda.gov/medwatch](http://www.fda.gov/medwatch)).

*(Reprinted from The Houston Chronicle, April 20, 2008)*

# Will I Live To Be 80?

(taken from a circulating email)

I recently picked a new primary care physician. After 2 visits and exhaustive lab tests, he said I was doing 'fairly well' for my age. A little concerned about the comment, I couldn't resist asking him, "Do you think I'll live to be 80?" He asked, "Do you smoke or drink?"

"Oh no," I replied. "I'm not doing either." Then he asked, "Do you eat rib eye steaks and barbecued ribs?"

I said, "No, my other doctor said red meat is unhealthy!" "Do you spend a lot of time in the sun doing things such as playing golf, sailing, hiking or bicycling?"

"No, I don't", I said. He said, "Do you gamble, drive fast cars, or have a lot of sex?"

"No," I said, "I don't do any of those things."

He looked at me sternly and said, "Then why do you care if you live to be 80?"

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## June Celebrations

### Birthdays

1<sup>st</sup> Tom Post  
2<sup>nd</sup> Charlotte Key  
5<sup>th</sup> Jack Fenner  
6<sup>th</sup> Anita Bjorling  
Maxine Rye  
9<sup>th</sup> Mike Robinson  
14<sup>th</sup> Margie Ellison  
15<sup>th</sup> Leland Bleck  
16<sup>th</sup> Lynda Purdom  
28<sup>th</sup> Bonnie Welle  
Edd Hardin  
30<sup>th</sup> Jeremy Hansche

### Anniversaries

7<sup>th</sup> Jaan & Millie Lill  
Susanne & Steve Chastain  
9<sup>th</sup> John & Karen Dulany  
12<sup>th</sup> Linda & John Booth  
15<sup>th</sup> David & Ricky Bridges  
24<sup>th</sup> Rain & Leland Bleck  
Rick & Jeri Dillon  
25<sup>th</sup> Dick & Phyllis Bischof  
27<sup>th</sup> Bill & Bonnie Welle  
Vern & Janet Williams

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*It's not hard to meet expenses... they're everywhere.*

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## July Celebrations

### Birthdays

4<sup>th</sup> Mary Ellen Hemby  
6<sup>th</sup> Virginia Dugger  
9<sup>th</sup> Stella Cade  
12<sup>th</sup> Don Young  
14<sup>th</sup> Mary Young  
16<sup>th</sup> Kerry Nordin

### Birthdays

20<sup>th</sup> Bill Cade  
Irma Launius  
22<sup>nd</sup> Sue Karnes  
24<sup>th</sup> Charlie Greulich  
Rox McKenzie  
25<sup>th</sup> Bobbie Bateman

### Anniversaries

3<sup>rd</sup> Randy & Annie Bassham  
15<sup>th</sup> Reg & Bobbie Bateman

# Sudoku

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

Answer to this puzzle will be in next month’s issue due to an overwhelming number of requests by the members at the 2008 post-polio reunion.