

Impact of PPS on a Polio Partner

By Dave Van Aken

I am not an expert. I am a husband and spouse. I am a Polio Partner, not a caregiver. There is a difference. A Partner is anyone who works to better someone's PPS situation. They can be a spouse, a brother/sister, a child or a friend...and I am a survivor. If necessary, I will adapt every day to our changing situation. When PPS came into our lives, we Partners faced a choice – fight or flight. We chose to stay and fight. But what are we fighting for? I am fighting to maintain my wife's quality of life, as well as our collective quality of life. My guess is we are each trying to accomplish the same thing.

The one thing I have found that is true about PPS is each survivor is different. As each survivor is different, then each of our situations is different. We do, however, face one common theme – coping with PPS involves a series of compromises. We must remain flexible and tolerant, as we must adjust to our Partner's ever-changing condition.

So, how are the Polio Partners impacted by PPS? I believe there are three main impacts on the Polio family – Financial, Physical, and Emotional.

Financial Impact

It simply costs more to be disabled. Your family may have a loss in income. You may become the primary income producer for the family. Adaptive devices become necessary or required: braces, scooters, or power chairs. Modifications to your home could include ramps, grab bars, higher toilets, or even a new home. All create extra expense.

Traveling requires more forethought and planning. Depending on your situation, the impromptu “escape” trips may be a thing of the past. We trade in our sports cars for minivans to accommodate scooters or electric chairs. Public transportation offers even more challenges. Trains and plane service have advanced in dealing with the handicapped, but often have a way to go to become trouble-free.

Physical Impact

We have all heard “Conserve to Preserve.” Most Polio Survivors have had this preached to them repeatedly. We need to pay attention to this as well. We try to have our Partners conserve their muscles and adapt to new methods and devices. We should listen to our own advice and use technology, children, or friends to help share our increased load. We are aging as well and our own aches and pains will affect our ability to provide care for our Partners.

Emotional Impact

Early on, when we are naïve or unknowledgeable, our expectations can be unrealistic. “If you do all of this, then you'll get better.” “When you get better, we'll do this and that.” We (some older Partners in one of our discussions) scared the “hell” out of a new Partner. As she admitted later, she expected her husband to beat this and they would carry on with the plans they had envisioned for themselves.

Anger, depression, anxiety. Our Partners thought they beat polio over 30 years ago, and now it has come back to haunt them. Their bodies are giving out, betraying them, and losing functionality. They lose “face” as they succumb to the adaptive devices in

an effort to save what is left. Is it any wonder, they get angry at the world, and we, sometimes, bear the brunt of it?

We hurt as we watch our Spouse's suffer both emotionally and physically. At times, they lose their sense of self. As a culture, what we do for a living or where we volunteer often defines us. As our Spouses curtail this type activity, there is a sense of loss. This can trigger a sense of depression, which we, as Partners, try to cope with and ease our Partner out of it.

There is the physical side, or pain we watch our loved ones endure. We ache to be able to ease some of the pain they suffer. In most cases, we pick up extra chores so they don't have to do it.

We grieve over our futures. We – as couples or as individuals – had dreams and desires. While they do not have to be abandoned, they must be reevaluated.

Mid to Late Stages - As we grow older and more experienced with PPS, continual adjustments have become the norm. We must accept each situational change and move forward.

Fatigue periods can become common. These can add more anxiety, anger or depression for our "Type A" spouses. Polio fatigue crashes are real. Linda "crashed" in October of last year. For seven weeks, she was flat on her back. I adjusted. I did the housework, the laundry, and the cooking. Before October, my repartee in the kitchen was scrambled eggs or waffles. But, I provided Linda with hours of entertainment as she directed my efforts in the kitchen. We didn't starve and weren't poisoned, so I guess we did ok. [Guys – spend some time in the kitchen before you have to. It's a survival skill!]

The hardest part I find in being a Partner is watching the sometimes rapid decline of one of our Polio friends. We all know it may come. We hope and pray it won't. So, we nag and cajole our Partners and friends into behaving and conserving their abilities. A Partner friend confided that their biggest fear was not being physically able to care for their spouse. On the other side, their Survivor's biggest fear was becoming a burden on the Partner. Our fears are so much the same.

Friends and Family

Unfortunately, family and friends often judge our Partners by their appearance. What does fatigue and muscle weakness look like? Part, if not most, of the problem is that they look so normal. There is no disfigurement. They may have a slight limp, which has become more pronounced now, and they should always use their canes or crutches. Friends can't understand why they can't do this activity or that. They see them in their scooters, or using their canes doing the activities they choose. Why can't they do it all just like they used to?

Friends and family do not understand the Survivor must make choices each and every day about the most mundane things. My wife has a system she calls "energy presents." Every activity uses some energy presents. She has about 10 presents each day. So she monitors what she does, and tries not to exceed her 10 presents per day. But, sometimes she does, and she must take extra rest. And if she really blows it out, we both may enjoy the short term, but both of us will suffer the consequences.

What Can We, as Partners, Do?

Communicate, communicate, and communicate! You and your Partner must communicate on your fears, your concerns, and your plans on how to move forward. Sometimes these discussions can become heated – I prefer to think of them as passionate discussions (I think every relationship needs passion). The more emotional and honest, the better the understanding between both of you.

Educate yourself – Knowledge is Power. Find out as much as you can about Polio and PPS. Apply what you learn to your situation.

Educate your family and friends. You need the help, and your Partner needs the support. If your family and friends don't get it, you have a choice – either continue to educate or drop off (another loss). It's your energy you are using, thus your choice.

Take Care of Yourself. Take charge of your life; do not let your Partner's disability or illness always take center stage. Be good to yourself, you deserve it. You are doing a very hard job. When people offer to help, let them. The task may not be done "the way you would," but it will be done. Grieve for your losses, and then begin dreaming new dreams. Trust your instincts. They will be right most of the time.

Seek support from other Partners. There is strength in knowing you are not alone. Many of the Survivors belong to a PPS support group. Do you, as a Partner, attend these meetings? Do other Partners attend? Grab some of the other Partners and go get some coffee while the PPSers meet. Encourage your support group to give you an opportunity to meet separately. Often a general discussion is all the agenda needed.

Central VA PPS group discovered this at our annual retreat about 4 years ago. We had a Partners forum where we openly discussed our concerns, fear, and things that worked. We invited a minister to come and facilitate our first meeting. Since that meeting, I have been facilitating meetings for Partners about 2 times each year. Our discussions are usually about what is going on in our lives at that moment, and we share what works for us and what doesn't.

There are some online support groups, but mostly they deal with PPS. There are some Caregiving web pages, which provide some good information, but not strictly on PPS. I don't have a lot of experience with these, because like most of us, we Partners don't have a lot of free time anyway.

As I said in the beginning, I am not an expert. If you have questions about a Partner's session, I would be happy to help. If you have specific questions about Partnering, I would be glad to help. I have some special Partner friends who have more experience than I do, so maybe we can provide an answer. I can be reached at DvanAken@aol.com but be certain to mention PPS in the subject title or I might not open your message.