

Periodic Paralysis and Your Friends “WHAT FRIENDS?”

Although I was born with Periodic Paralysis(PP): Andersen-Tawil Syndrome(ATS), throughout most of my life I have always been a very social being. My formative years were spent in a family with three brothers and too many cousins to count, numerous aunts and uncles and family friends. I had friends who lived in my neighborhood and I had friends at school. I belonged to a Girl Scout Troop and went to Girl Scout camp every summer. I also belonged to the YWCA and spent time in day camp every summer. I had friends at church and spent much time in church activities. As a teenager, I belonged to a “group” of kids and we spent a lot of time meeting new kids in other “groups”. I spent much of my time socializing with peers and talking on the phone.

As an adult, I spent much of my time with family and my in-laws. I always knew my neighbors. I was active at church. I had jobs over the years and many co-workers became my friends. I always knew the parents of my children’s friends. I had a group of friends that I socialized with, some were friends I had as children. When I attended college I had friends and belonged to study groups.

When we built our home and moved to the mountains, we had a small community of neighbors, about 6 families, with whom we socialized constantly. At the drop of a hat and for any reason we would get together with good food, good conversation and lots of laughs around a campfire. If we weren’t entertaining friends and neighbors our mountain home was loaded with family on holidays and weekends.

Early on, I would notice being very tired and weak after our big weekends or holidays. Even a simple dinner with friends would wipe me out. I assumed I just did too much. At the same time, I was getting weaker physically and developing more and more symptoms. The doctors were giving me more medications. I had to stop working. I was deemed disabled.

We began to entertain less and less. We began to go visiting less and less. I talked on the phone less and less. I seldom left the cabin. I had less and less energy. Soon we were not socializing at all except for family gatherings, at which the kids were doing most of the preparations.

I found I had only a certain amount of energy in me to expend each day. I had just enough to do the things I had to do, a little cooking and cleaning and maybe a shower. If I had to shop or do laundry, I was be wiped out for a few days afterward. I had not enough energy to do what I needed or wanted to do in a day. This left nothing left in me for socializing, including family. Talking on the phone even became a chore.

We had to move away from our mountain home with three stories because I could not walk up the stairs any longer. It was a huge house and too much work for me. It broke our hearts but we left our family behind and moved to a small town in Grants Pass, Oregon for a better climate. We had hoped our kids would follow us. but they never did.

We bought a small house that needed to be remodeled. Calvin did a nice job, but we were on top of a mountain with no place to go for short walks or exercise. We were very isolated with no close neighbors. One of our closest neighbors made attempts to be social. I had no energy and became even sicker so we just never did more than visit a few times. Another couple was introduced to us through a relative. We had dinner once and then I was too sick to ever have them over to reciprocate. We met one more couple through a business deal and got together a few times, but then I reached the end physically.

We had to move into town and into a senior mobile home park. It is on level ground for easier access and I can use my motorized wheelchair to get around. We found a wonderful home right on the Rogue River and the river flowing by brings me some peace of mind. However, we do not socialize or go to any of the activities due to my health. We know very few people here and have made no friends.

I am not able to do much more than walk across my house. I spend most of my time in a recliner attached to an oxygen machine in order to breathe. I suffer from exercise intolerance and the electrical workings of my heart are damaged. I go in and out of paralysis. I am unable to do anything that may cause a rise in adrenalin or epinephrine.

Talking on the phone takes every ounce of my energy, so my conversations are short and usually limited to family members. I can no longer cook or clean or entertain. Our friends and acquaintances have stopped trying to make plans with us for understandable reasons. The only person I see other than my husband is my therapist. She comes to our home once a week to help me deal with my failing health and isolation. She has become like a friend and has been wonderful to me.

And so, as a casualty of Period Paralysis: Andersen-Tawil Syndrome, I have a few real friends with whom I see in person if they drop by or keep in contact with an occasional phone call. However, I spend most of my time sitting in my chair with my lap top computer. I am able to communicate with the outside world this way without draining my energy. I have nearly 200 “friends” on Face Book. Over forty of them are family members with whom I keep up on the latest gossip and activities and several of them are life-long friends, even a few from elementary school. Some of my “friends” have PP and are in varying degrees of disability. We support each other. Others play games with me. Many of them are genealogy cousins, for whom, I do genealogy research and share information. I spend much of my time writing for and developing the Periodic Paralysis Network; offering help and support to others like me. I keep on top of politics, have debates with others, share jokes with cousins, and use Skype to talk with my grandson.

Next to my husband, my laptop is my best “friend”. It affords an entire world of friends for me in what otherwise would be a very lonely life.

Most people with PP will not become as disabled as me and will probably be able to socialize within his or her specific limitations. Many will lose friends because they will not be able to keep up with the energy it takes to entertain and keep friends. There will be

a few who are much like me. Their friends will desert them and they may spend much of their time alone. If at all possible they should get a lap top computer or open the one they have and begin to make friends. Join the boards for people with PP. They will find many people like themselves. They will become friends. They will truly understand you, offer support to you and exchange ideas and information with you. In this world of technology we are truly no longer alone.