

Periodic Paralysis and Caregivers “GIVE ME A BREAK”

By Susan Q. Knittle-Hunter

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I am 62 years old and on February 2, 2011, I was diagnosed with Periodic Paralysis: Andersen-Tawil Syndrome. I have had episodes of partial and total paralysis for many years. During the episodes, my potassium shifts are low (hypokalemia), high (hyperkalemia) and within the normal ranges (normokalemia). Due to several misdiagnoses and a lack of proper diagnosis and treatment for over 50 years, I have become totally and permanently disabled with weak muscles throughout my body including those involved with my vision, digestion, breathing and my heart. I must be on oxygen constantly and cannot exert myself in any way. The electrical workings of my heart are defective. I have had a heart loop monitor inserted in my chest to monitor the tachycardia and arrhythmias that includes long QT interval beats. I now spend my days in a recliner, unable to walk farther than across a room. I must use a motorized wheelchair for anything farther. If I did not have the help of my husband, Calvin, of 30 years, I would have to live in an assisted living program. He has become my caregiver.

Through the past years of my physical decline, I have had to give up my career as a special education teacher, my hobbies to include hiking, walking, swimming, exercising, fishing, camping, traveling, shopping, cooking and baking. I had to sell, and move away from, a beautiful home my husband and I built in the mountains of Utah. I had to move far away from my family in order to live in a better climate. I can no longer drive our car. I have lost many friends, because I could not keep up with them or entertain any longer. My husband has lost all of this also.

Calvin is disabled too, but not as severe as me. He does all of the shopping, cooking, cleaning, yard work, paying the bills, maintains the house and car and the laundry. He also drives me to doctor appointments, and monitors my vitals to include my potassium levels, blood sugar levels, ph levels, oxygen levels, heart rate, blood pressure and body temperature. He does this to know when to give me potassium if my levels are too low or when try something else if my potassium levels are too high. He does his best to keep me warm and comfortable.

When I go into paralysis, he watches me very closely. I become totally paralyzed. I am unable to move in any way, I cannot speak nor can I open my eyes. He monitors my vitals during an episode; potassium levels, blood sugar levels, ph levels, oxygen levels, heart rate, blood pressure and body temperature. And, he has to make sure that I am not choking, that my breathing is not too shallow or too fast or that it does not stop. And; he has to monitor my heart because I may go into cardiac arrest and he must be ready to do CPR while he calls 911. He has to make sure not to move me because damage can be

done to my joints when I am in paralysis. But, he has to make sure my neck and head are not kinked and in pain and carefully adjusts me as necessary. If my potassium levels get too high, he may need to call for an ambulance because that means I have gone into metabolic acidosis, a serious and potentially fatal condition.

As he does all of that he talks to me. He tells me the result of each test. He knows I can hear him and so he reassures me. These episodes may last from fifteen minutes to three or four hours. He is with me and monitors me through the entire episode. As the paralysis subsides, I am very weak and have difficulty speaking. I will usually have to suddenly urinate due to what is called the potassium “dumping”. I need to get to the bathroom quickly. He will have to help me to my walker and push me to the bathroom and help me on to the toilet and then keep me from falling (This has not been easy for me to deal with). Then, depending on the time of day, he will undress me, put me in my nightgown and put me to bed.

Calvin has researched every aspect of Periodic Paralysis and Andersen-Tawil Syndrome and continues to do so everyday. He has argued with doctors. He has fought with insurance companies. He has driven me 100’s of miles to see specialist as I had episodes in the car all along the way. He fought to get oxygen for me, which saved my life. He researched insurance companies until he found one that does not require referrals. He explains everything he can about my disease to those who need to know. He handles all the billing issues. He is with me at every doctor appointment, asking questions and providing them the most recent information about PP and my vitals. He created charts to record every bit of information. He developed a diet for me and helps me to stick with it. He has helped me develop the Periodic Paralysis Network.

Calvin is my hero. I do not know how he does this day after day, week after week and month after month; soon to be year after year. He is an amazing man and I am thankful to have him in my life.

When I tell him how sad I am that things are as they are and apologize to him, he tells me not to apologize. He says, “You would do the same for me if I was the one who was sick like you are”. He is very humble about what he does.

I see it wearing on him at times and wish I could do something for him. I know it must be difficult watching me going through the episodes of paralysis. I know it must be difficult for him to see me so ill. I know it must be difficult for him to see me going downhill physically. I know it must be difficult facing the fact that I am probably dying right in front of his eyes. I know it must be difficult to know that the doctors feel they have done all they can do for me. I know it is difficult for him to fight to keep me alive.

I wish he could take a break from all he must do for me, but he never asks for one. I had hoped we could get respite care from the MDA but that plan fell through, in an unfortunate set of circumstances. We have no close family. The nearest relative is 250 miles away. We have no close friends. We have too much income to qualify for respite

services through the county or state. The home healthcare nursing services, through my insurance, does not offer respite care.

For now, I guess we are stuck with each other, “in sickness and in health; until death we do part”. I love him so very much and am thankful every day for him. He is truly my hero.

I realize most people with Periodic Paralysis will not end up as seriously ill and permanently disabled as me. They are lucky. However, I know of several people who live alone and deal with symptoms much like my own. They have no caregiver. It is frightening for them and safety is an issue. I am not sure how they are able to deal with the issues we face. They need someone to help them. They need caregivers. I hope they will be able to get the help they need through the MDA, insurance or their local community. No one should have to go through this alone.

Caregivers for Disabled Adults

By Charlotte Hoaks

Making the decision to care for a disabled adult is a life altering resolution to an already difficult situation. Whether a sibling or non-family member, the decision to become a caregiver for a disabled adult means change. Once, a mother of a disabled child once said it was like learning to live in Holland. In a lot of ways, her comparison was valid. As the parent of a disabled child you learn a new language and how to live in a completely new environment with a new focus in life. Every choice made reflects “what’s best for my child”.

When you make the decision to accept responsibility for a disabled adult, it mirrors many of the same issues. The only trouble is, the inroads made over a lifetime of care giving by parents are not automatically transferred to the new care giver. State, county, and local contacts for assistance programs are seldom passed along. Dealing with waiver and support programs can be confusing and at times, a gauntlet most people find impossible to manage. That said, if a caregiver you must be, then first face some facts. You’re moving to Holland and your life is changing.

My experience is in Texas and that said, I will refer to state specific issues. Each state will have similar initiatives; some will provide better programs, while other states will offer little in supported services. First do an Internet search of state services.

<http://www.ssa.gov/>

[<http://www.dars.state.tx.us/>]

<http://www.thearc.org/NetCommunity/Page.aspx?&pid=1400&srcid=183>

<http://www.hhsc.state.tx.us/Medicaid/contacts.html>

[<http://www.workforcelink.com/html/txrehab.asp>]

<http://www.acf.hhs.gov/programs/pcpid/index.html>

Use your state as the source and search for disability services. In the search engine text option use words; “Your county” Your State” Disability, Rehabilitation, Services. Then Search. If disabled, most adults qualify for Social Security Income (SSI). It’s not much assistance financially, but with it the disabled adult qualifies for Medicaid. That covers some financial assistance and medical insurance. That’s basics but we all know, that’s not the ultimate goal.

This is the time to get real investigative. As you well know, individuals with a disability have varying developmental levels. You’ve stepped up to the plate, so realistically, where do YOU want to go from here. More is better when it comes to independence but always keep in mind each person’s limitations. For this article, I’m assuming there is a degree of independence possible. Self care and communicative skills are required to move beyond custodial care and into the world of community integration. All things considered, you must be the judge of the disabled person’s ability to learn job skills and integrate socially. Training time is not important. Weather it takes a week or a month, learning a skill is the key. Rule of thumb, if a disabled person can keep the house, his room and bathroom clean, than he can be a dining room attendant at a fast food restaurant. If the disabled person conducts themselves appropriately in social settings, they’re ready for community integration.

Find a program. Make calls. Don’t stop reaching out. The Internet is the best possible search tool. Don’t stop until you find a program that fits your disabled adult’s needs.

Persistence is important. Sign up for every qualifying program, don’t stop calling until it’s active and finally and foremost keep good records. Use an expanding file folder, make a file folder for each program, save correspondence, make copies of letters and forms you send out and keep notes on every verbal and telephone conversation.

It’s hard to imagine administrators of programs could possibly be selective in application of policies but it happens all the time. If a program has a waiting list, ask the number on the list. Call back every few months and make someone provide a status. Get names. Be able to tell the next person the history on a subject including dates and who you spoke with.

Last but definitely not least. Join a support group. Association of Retarded Citizens (ARC) is a national organization. The ARC has social events for the disabled, caregiver training and state government inter-action and advocacy programs.

Charlotte Hoaks is the mother of a disabled 34 year old adult. Her son is currently working 15 hours a week at Wendy's as a dining room attendant and has an active social life with family and ARC friends. As a single parent of a disabled child, Charlotte has learned by trial and error about navigating the "system" and living in Holland. Her favorite response when asked about raising her son alone: I didn't put it on my list during high school career day, but I wouldn't have missed it for anything. I'm the woman I am today because I raised a special person. He taught me strength, compassion, and peace of heart.

ARC information: <http://www.thearc.org/NetCommunity/Page.aspx?&pid=183&srcid=-2>

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<http://ezinearticles.com/?Caregivers-for-Disabled-Adults&id=775804>

Narrative on Disability and Caregivers

My last *HuffPost* blog elicited a wide variety of comments about whether someone would want to live after a catastrophic injury. There was a thread in the comments from able-bodied individuals that suggested that people with a serious disability would have no "quality" in their lives and that life may not be worth living.

Whether they intended to or not, it appeared that some people without a disability were not just speaking for themselves, but also for the disabled community. This is a common and disturbing attitude that society holds about people with serious disabilities. There is a false belief system that the dreams, aspirations and desires of an "able-bodied" person change the minute they become sick or disabled. Our society devalues a person with a disability and assumes that they could not possibly want the same things as an able-bodied person. Nothing could be further from the truth.

I also heard from people who told me about caring for someone with a disability and both the trials and the richness of that experience. You might be surprised to learn that they are people you work with or your neighbors down the street.

Our readers referred to end-of-life decisions such as removing a patient from life-support systems or withholding life-saving measures, but most disabilities present a very different set of problems. We often fail to recognize and address the issues that impact the quality of life for the millions of disabled people in this country. Many lessons can be learned for all of us by examining the factors that affect the quality of our lives. We speak of injecting more quality into our lives, but what are the components of this amorphous term? Bryan Jennett, a famous neurosurgeon, addressed this issue for brain injury survivors back in 1975. The principles he articulated hold true not only for disabled individuals but for all of us. The seemingly mundane activities that we take for granted are the key factors in determining the "quality" in our lives. Rather than assume it is not a life worth living, it is much more productive to look at how we can meet the needs of people with disabilities.

Personal Care

Able-bodied individuals take for granted the ability to go to the bathroom, bathe or brush their teeth without assistance. I have had patients who refuse to go home because they could not endure the embarrassment of a spouse cleaning them after going to the bathroom. The ability to master and have control over our bodily functions is central to a sense of mastery over our lives and correlates directly with our sense of self-esteem. Few animals survive if they depend on others for food and basic maintenance. For man, it is an issue of quality rather than survival. We take our morning "routine" for granted while the disabled individual may spend months mastering these "basic" tasks -- tasks that equate with quality survival.

Mobility

When I feel thirsty, I stop what I am doing and find something to drink. I go to the bathroom when I want to go and when I need to go. The disabled person who is dependent for mobility is at the mercy of his caregiver or helpful citizen. In a hospital they may sit in their room or hall until the overworked aide has the time to put them back to bed or take them to dinner. They are no longer on their own schedule, but on that of others. Independence in mobility is key to the quality of one's life. If they can propel their own wheelchair or ambulate independently they may be able to live alone. If they can transfer themselves from a wheel chair to a commode, they can stay alone during the day.

Social Relationships

That which makes us most human may be our ability to form relationships. We may not always form satisfactory relationships, but at least the potential is there. We have peers, colleagues, buddies, lovers and spouses. Freud described the balanced triangle of life as "to love-to work-to play." Disabled individuals see the triangle fractured in several ways.

Previous relationships may shatter because the foundations upon which they were built have been altered through physical, behavioral or cognitive changes. That which a partner loved most may no longer be present and that which they liked the least may now be exaggerated. The ability to form new relationships may be altered by being thrown in to a "new" peer group of the physically or mentally disabled, while the friends who initially visited at the hospital have now retreated to the safe haven of their peer group. The social fabric that was once tightly woven starts to unravel and the "quality" supplied through social relationships is diminished.

Work

Work is another corner of the triangle. Through work we enhance our self-esteem, obtain recognition and develop a sense of self worth. At work I interact with a peer group, develop social relationships and find avenues for recognition. It is this concept of present day satisfaction that is so important. Most of us have a picture in our mind's eye of what we should be doing and our capabilities. Once achieved, few are willing to settle for less. If I tried to return to work after becoming disabled, I would probably not settle for less than being the Medical Director of a major rehabilitation hospital. Many injured or disabled workers face this dilemma, being asked to assume a new role that is perceived as less important or less interesting. The vocational rehabilitation of people with disabilities presents a special challenge because the hours spent in the work environment work are a major factor in the quality of one's life.

Future Prospects

While I was writing, my mind wandered to my next vacation, plans for the remainder of the year and what topics might be good ideas for future blogs. Our future plans fuel the hopes and aspirations of what we can still attain. Catastrophic injuries and illnesses may bring a sudden halt to an individual's or family's future plans as they do not know what to expect next. Serious illnesses and injuries suddenly change one's ability to pursue vocational and leisure interests. A lifestyle predicated on intellectual or physical strengths will now need to be modified. We must assist the disabled person so they can reach a point where they not only can accept their present day situation, but see hope and fulfillment in the future.

These are lessons not only for the disabled, but for all of us. It should not take a "near death experience" for us to reevaluate the importance of social and work relationships and to address the priorities in our lives. We all take these for granted until they are gone, forever.

For more information visit: <http://www.richardsenelick.com>.