How Bad Will it Get?
"I DO WHAT I CAN, WHEN I CAN, IF I CAN"

By Susan Q. Knittle-Hunter

To begin this article I decided to add a few passages I found in my research regarding what is going to happen to us now that we know we have Periodic Paralysis. Most of them are simply written by professional people who have no form of Periodic Paralysis. Except for one, there are only two to three sentences detailing the rest of our lives!!!!

Prognosis

While the disability can range from minor, occasional weakness to permanent muscle damage, inability to hold a normal job and use of a powerchair, most people function fairly well with drugs and lifestyle changes.
http://www.answers.com/topic/periodic-paralysis

What is the prognosis?

The prognosis for the familial periodic paralyses varies. Chronic attacks may result in progressive weakness that persists between attacks. Some cases respond well to treatment, which can prevent or reverse progressive muscle weakness.
http://www.ninds.nih.gov/disorders/periodic_paralysis/periodic_paralysis.htm

Prognosis

The prognosis for periodic paralysis varies. Over activity, bad diet or simply an unfortunate gene mutation can lead to a type of chronic, low level weakness called an "abortive attack," or to permanent muscle damage. Abortive attacks often respond to extra potassium, cutting carbohydrates, getting plenty of rest, increasing doses of medication and gentle daily exercise such as short walks. Permanent muscle weakness is just what it sounds like, permanent, irreparable damage to the muscles. Vacuoles and tubular aggregates form and destroy healthy muscle tissue. This type of damage should show on a muscle biopsy. Not even anabolic steroids can bring these damaged muscles back.
Life span is expected to be normal, but attacks can drop potassium to levels low enough to cause life threatening breathing problems or heart rhythm difficulties. Patients often report muscle pain and cognitive problems during attacks. Migraines occur in up to 50% of all hypokalemic periodic paralysis patients and may include less common symptoms like phantom smells, sensitivity to light and sound or loss of words. Medical literatures states that muscle strength is normal between attacks, but patients tell a different story. "Normal" for them is not exactly the same as "normal" for everyone else.
Because there are dozens of possible gene mutations, some drugs and treatments that work fine for one patient will not work for another. For example, most patients do well on acetazolamide, but some don't. Some patients will do well with extra magnesium (the body's natural ion channel blocker) or fish oil, while these same nutrients will make other

patients worse. Patients and care givers should take extreme caution with all new drugs and treatment plans.

http://en.wikipedia.org/wiki/Hypokalemic_periodic_paralysis

Outlook (Prognosis)

Hypokalemic periodic paralysis responds well to treatment. Treatment may prevent, and even reverse, progressive muscle weakness. Although muscle strength is initially normal between attacks, repeated attacks may eventually cause worsening and permanent muscle weakness between attacks.

Possible Complications

- *Kidney stones (a side effect of acetazolamide)*
- *Heart arrhythmias during attacks*
- *Difficulty breathing, speaking, or swallowing during attacks (rare)*
- *Progressive muscle weakness*

http://info.baylorhealth.com/HIE%20Multimedia/1/000312.htm

Prognosis

While the disability can range from minor, occasional weakness to permanent muscle damage, inability to hold a normal job and use of a powerchair, most people function fairly well with drugs and lifestyle changes. On a lighter note, people with periodic paralysis are sometimes lovingly called Possums because they play dead when startled or stressed. (HOW FUNNY!!!! NEVER HEARD THIS BEFORE!!!!)

http://www.lumrix.net/medical/channelopathy/periodic_paralysis.html

Expectations (prognosis)

Chronic attacks may eventually result in progressive muscle weakness that is present even between attacks. Hypokalemic periodic paralysis responds well to treatment. Treatment may prevent, and even reverse, progressive muscle weakness.

http://www.medhelp.org/medical-information/show/2181/Hypokalemic-periodic-paralysis?page=6

When I began to research I wanted to know what to expect. How long will I live? How bad will I get? Can this disease be reversed if I get proper treatment? Will I lose my ability to walk? Will I ever drive again? Will I need to be in an assisted living program? Is there medication to stop the total paralytic episodes? What are my chances of dying from the long QT interval heart beat? Will my breathing continue to get more difficult until I can no longer breathe on my own? Is there any medication I can take if I get another bladder infection? What happens if I need an operation and can't use anesthetics?

What can I do to stop the pain in my shoulder and back since I cannot take any pain medications? When I go into cardiac arrest, is it worth trying to save me? Will I end up on dialysis due to kidney failure? Can I travel? What will happen if I end up in the ER again and they can't help me with any medications?

The short blurbs above are all I was able to locate. There are no doctors who can tell me. My renal specialist told me that he is unable do anymore for me since the diamox did not work. My neurologist tells me that he does not know what to do for me. My cardiologist says, my heart condition, due to the PP, is "not treatable" for me. I am, "not a candidate for a pacemaker", "possibly a defibrillator later". My Primary Care Physician (PCP) will not treat anything that has to do with my disease. Even the MDA doctors I saw did not recognize PP nor did they know how to diagnose it correctly. I was told by one of the MDA Healthcare Coordinators, that they need me to educate the MDA doctors so they will know how to treat me. This is not at all comforting. No one can tell me how to treat my symptoms or what to expect.

Here is what I do know about myself and can tell you in answer to the above questions:

I am 62 years old and was newly diagnosed with Periodic Paralysis (PP) on February 7, 2011. The kind I have is Andersen-Tawil Syndrome Type 2. 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 arrythmias, that include 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, I would have to live in an assisted living program. I was misdiagnosed for many years. The medications given to me made me worse.

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 in the mountains of Utah. I can no longer drive. I have lost many friends, because I could not keep up with them or entertain any longer. I have lost contact with family members who did not understand or did not want to watch my decline or who thought I was a hypochondriac. I have lost the connection I once had with my grandchildren because I can no longer keep up with them or continue a meaningful relationship with them. The relationship with my husband has changed from husband and wife to caregiver and patient. Most of the over 30 doctors I have seen in the past 6 years have treated me poorly and like I was mentally ill.

I have spent the past several years working diligently to get a diagnosis and treatment for the ailment that cruelly stole the quality of my life. The most difficult part of this, for me,

is knowing that I may not have became this seriously ill if just one of the over 30 doctors I have seen in the last 6 years in Oregon and the many years before, would have taken me seriously.

The following quotes taken from the above passages give us a clue of what can happen, but the passages from which I pulled them insinuate it is not "normally" what happens. I am in contact with many people from around the world who would beg to differ with this. The following is more in line with what is happening to people with PP due to lack of diagnosis and treatment.

> ***"Permanent muscle weakness is just what it sounds like, permanent, irreparable damage to the muscles"***
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> ***"Life span is expected to be normal, but attacks can drop potassium to levels low enough to cause life threatening breathing problems or heart rhythm difficulties"***
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> ***"some drugs and treatments that work fine for one patient will not work for another."***
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> ***"repeated attacks may eventually cause worsening and permanent muscle weakness between attacks"***
>
> ***"Possible Complications***

- ***Kidney stones** (a side effect of acetazolamide)*
- ***Heart arrhythmias during attacks***
- ***Difficulty breathing**, speaking, or swallowing during attacks (rare)*
- ***Progressive muscle weakness"***

> ***"……permanent muscle damage, inability to hold a normal job and use of a powerchair,"***

In my opinion, the truth is, the majority of people with this disease end up like me; very, very ill; but they are mis-diagnosed, under-diagnosed, called mentally ill, or hypochondriacs. They are diagnosed as suffering from conversion disorder, or having pseudo seizures. They are laughed at and scoffed at. They are told they are "too old" or it is not possible because they are "black". They are given medications that make them worse. Doctors dismiss them and ridicule them and lie about them in the medical records. They do not get the medication or treatments they need. Then they die of things such as, "unknown" muscle wasting disease, accidental drowning in a pool or bathtub, cardiac arrest at age 40, stroke, or failure to thrive. The worse is from suicide; because if your doctors don't believe you, how can your family members be expected to believe you. They just give up.

Our main reason for creating this website, is for these people. They need to be diagnosed and get the proper medications and treatment before it is too late. We want to help them. We are hopeful that the doctors who see this website will become more aware of this disease and gain enough information to begin to appropriately diagnosing their patients with Periodic Paralysis before it is too late.

In conclusion, many people with Periodic Paralysis will live normal life spans and their disability will be minor with occasional weakness. Some may actually not even have episodes of paralysis. Others will have moderate disability and receive proper medical treatment and medication. They will respond well, and may even reverse some of their weakness. But, others with Periodic Paralysis, will have mild, moderate or severe disability and they will not receive proper diagnoses or treatment. They will become more disabled and suffer needlessly and may die needlessly. I cannot at this time tell anyone what to expect or how bad it will get.

No matter what type of Periodic Paralysis one may have, or what degree off weakness or disability he or she may experience; “we do what we can, when we can, if we can”. (Thank you Jean)