

Periodic Paralysis and the ER “BE AFRAID, BE VERY AFRAID”

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Periodic Paralysis and the ER...The Narrative

The following narrative and article is difficult for me to write. Going through my medical records is stressful due to all of the negative things written about me, the misdiagnoses, the unkindness I endured, the opportunities missed by the doctors to treat me appropriately, the horrible reactions to the medication I suffered and the fear I have been left with when I think about returning to the emergency room (ER). I have contemplated how I was going to write this and after much thought, I have decided to tell the experiences in as much detail as I can, so the reader can understand my frustration and fear. By sharing my experiences in this manner, I hope to help others avoid what happened to my husband and me in the ER and hospital. After writing my experiences, I will outline a plan to help others avoid the pitfalls of the emergency room.

I found myself in the emergency room (ER) of my nearest hospital, Three Rivers Hospital in Grants Pass, Oregon on 4 different occasions due to symptoms related to Periodic Paralysis. Three of those times I was taken by ambulance and the last time my husband drove me. Three times I was admitted for further observation. Each time I was released, I had no diagnosis or a misdiagnosis. Each time I was given medications that made me worse. Each time I was mistreated. My hospital records are filled with lies and misleading statements, misinformation and misdiagnosed conditions such as "pseudo" seizures. These have followed me since my first visit to the ER and continued to interfere with getting a diagnosis and proper treatment. It has been a life-threatening and continuing nightmare that could have been avoided if someone in the ER or the hospital had taken me, my husband and my symptoms seriously in the very beginning. Had this disease been caught earlier, I would not be as ill as I now am. I must presently be on oxygen 24 hours a day and my heart is seriously damaged.

My first ambulance ride and hospital stay was on September 30, 2008, as the result of heart palpitations (felt like it was beating out of my chest), tachycardia, arrhythmias and chest pain, early one morning. I was sitting at the computer when it began. I took a nitroglycerin tablet but it didn't help so I took another one. The pain continued so I got up

to walk to the bedroom to tell my husband. I could not walk and landed on the floor. I could not move. My husband heard and then came to help. He called 911. They arrived in what felt like a very long time. We lived 10 miles outside of town in the mountains. The EMTs placed me on a stretcher and wheeled me to the ambulance. They hooked me up to an IV and after checking all my vitals, asked me to sign a paper. I found I was unable to hold the pencil. After what seemed like another long period of time, we began the drive to the hospital.

Once at the hospital, I was doing a little better. I was hooked up to all of the necessary machines and equipment and all types of tests were performed. After several hours, the doctor walked in and was about to send me on my way, when suddenly my heart went into tachycardia. He changed his mind and had me admitted. During my stay I was continually on an IV which hurt horribly, but they would not fix it (A few weeks later I got phlebitis in my arm due to the IV and twice ended up in the ER to get an antibiotic for it.), and given several medications including tylenol, ativan, zophran, morphine and ambien. I had severe problems with walking and tremoring. After they gave me the morphine in my IV, I had an immediate reaction of sudden chest pain and palpitations and passed out. After one night and two days they discharged me, with an unknown diagnosis, but the suspicion that I had chest pains due to my acid reflux although the lab work indicated I had some type of event with my heart. I was given reglan, upon my discharge, a medication for the reflux. Once home I was doing better, but when I took the medication after dinner, I went into tardive dyskinesia, it lasted all evening and through the entire night.

What I know now, from the hospital records obtained recently, is that the labs indicated a possible heart attack or ischemia. Cardiac enzymes were elevated and testing ruled out pulmonary embolism. The doctor had me admitted to rule out an ischemic cardiac event. Ischemia is an absolute or relative shortage of the blood supply to an organ. It was not ruled out, but the cardiac event was obviously due to my periodic paralysis that we did not know I had at the time.

Had we known, I should not have been on an IV due to it causing paralysis to people with Periodic Paralysis. I should not have been given the other medications due to the side effects of them and the long QT interval problem. At the time we did not know what was wrong, but the effects at the hospital should have given them clues about what was going on. They were ignored or misinterpreted.

Unfortunately, the hospital recommended a coronary angiogram to be done after I left the hospital but neither my PCP nor cardiologist ever let me know about it. They both left town within a few months after that and it never happened. That could have been a turning point for me and I could have received some help, however, I didn't know about it and the new doctors did not follow-up.

In July of 2009, my life changed forever. At that point I had just found a new doctor because my previous doctor had left town for a better position in another state. The first doctor I went to told me I was too sick and that he would not be my physician. I left out

office crying my eyes out and went straight to the insurance company. They gave me the name of the doctor who was accepting new patients. I was able to get an appointment with him for the next morning. At first he seemed like a caring doctor but was upset with the number of medications I was taking, as was I. I was on 15 medications at the time. I was having ataxia, tremors, tachycardia, and palpitations and having trouble speaking. I told him I was very concerned over all the symptoms and asked if he would help me. He asked me to stop taking a few medications, which I did, and that I was to return to him future.

However on July 27, 2009, I had what appeared to be a seizure of some type. It was about the fourth time in the past 10 weeks, but by far, the very worst. I was unable to speak, walk or move in any way; I was totally paralyzed. I also had tremors and jerking in my muscles. These contractions throughout my body made it look like seizures. However, I was never unconscious. I knew everything that was happening. As before, I was wheeled to the ambulance and hooked up to an IV. My vitals were checked and one of the EMTs gave me some glucose by mouth. He told me I was hypoglycemic. I was lucky I did not choke on the honey-like substance. My heart rate was over 160 and I was given ativan. We finally left the driveway and headed to the hospital. Within a few minutes, my body was jerking worse, especially my legs and feet. They were beating against the back door of the ambulance.

By the time I got to the hospital, I was worse than when the ambulance arrived at my home. I assumed it was due to the glucose. I do not remember arriving at the hospital or what followed until I woke up while my husband was arguing with the doctors. They told my husband I was having seizures, but that they did not take care of seizures at the hospital and in the ER. They made my husband take me home with 12 tablets of ativan. Records show I did appear “ataxic” and “spastic” during some of my motor exams and the one of the doctors gave his reassurance that, “Sometimes it takes years to make diagnoses, especially when they are difficult and the symptoms presented are so varied, such as in this case”.

For the next two days, I remained in this state. I was in and out of consciousness. I was getting worse and unable to function. My husband, being concerned, called my new doctor and asked if there was any way I could be admitted to the hospital because he could not feed me or take care of me. After a few phone calls and my counselor/therapist getting involved, an ambulance arrived and took me back to the hospital. I do not remember much about that trip. I was admitted. The doctor was very angry and treated me horribly and put falsehoods in the records. At this point I could relate all of the lies and distortions, but have decided not to. Since that time, we know that all of the medications I was on and the ones the new doctor gave me and the ones from the hospital including the IVs, caused most of the symptoms. These symptoms combined with episodes of paralysis caused symptoms that they just did not understand. But being told to my face that he was referring me to a psychiatrist and that I was “making it all up” was horrifying and frightening when I was so ill.

I was sent home after a day. I spent the next several weeks in bed unable to do anything for myself. During that time, I found another doctor who put me on new medications without trying to discover what was wrong. The medications made me worse. My husband had to bring his sister in from another state to take care of me. I spent months recuperating and actually never have fully recovered.

At this point we realized we had to find another doctor. I could not find another M.D., and had to settle on a nurse practitioner. She was very helpful and was glad to take me as a patient. By now, we begin to realize that the medications were creating terrible symptoms for me. I got off of them as quickly as I could. We realized that almost all of the symptoms of ataxia, temors and problems with my speech had been related to medications. I stopped taking every medication I was on. Most of the ataxia, and tremors, etc stopped. Then, I began to have episodes of total paralysis. During them, I was unable to talk, open my eyes or move. I sometimes had chest pain, tachycardia and palpitations with them. They were frightening and we believed them to be related to my heart.

On the evening of February 19, 2010, I went into a serious episode. I was having trouble breathing during it for the first time. When I could speak, I asked my husband to call an ambulance. They arrived as before and put me on an IV. At the hospital, I was hooked up to the machines and the testing began anew. It was noted that I spoke in a “slow and low voice with flat affect” (my mouth was paralyzed), and that I had “weakness in my lower extremities”. My oxygen was at 96% saturation and my heart rate was 116 with a blood pressure of 147/58. They did admit me for observation.

Once admitted, I lay in the bed going in and out of paralysis, each one lasting between about 30 minutes to an hour. I know because all I could do was lay there and look at the clock when I was able to open my eyes as each episode eased up. During that time, the nurse looked in occasionally and told me that the doctor would be there soon. It was at least 3 hours from the first time she told me, that a doctor finally came to examine me. He wrote, “Initially, she is conversant but then she goes into an episode of being unresponsive and some mild shaking. It looks in my experience to be a ‘pseudo’ seizure.” He told me that and told me he was going to treat me with ativan. My husband told him not to do it. After he left, it was administered in my IV. Within a few minutes, I was very nauseous. The nurse brought me something for the nausea. I then threw up and the next thing I remember was waking up about 10 hours later in the morning.

I had no idea where I was. I thought they had moved me to another room. I tried to send my husband an email. When he got it he knew something was seriously wrong. I could not write or spell. He came and took me home before they could give me any more medication. He was afraid they would kill me if that were to happen. The hospital records say that I, “responded well to the medication”, that I was being discharged in “stable and significantly better medical condition after taking the ativan” which, “completely relieved my symptomatology suggestive that his diagnosis of ‘psuedo’ seizures was correct”.

This is an out and out lie...the medication knocked me out and when I regained consciousness, I could not talk or walk or do much of anything for myself. I was in and

out of the paralysis again. I was able to send an email...with a few words and a phone call to me from my husband confirmed my husband's worst fears. I was slurring my words and not making any sense to him. He came right away. He had to dress me and lift me into a wheelchair. He took me out of the hospital with no discharge plan. The record states that both my husband and I were "agreeable to the discharge plan". This "plan" lasted 30 minutes. This is ridiculous because there was no discharge plan.

That is the last time we dared to call an ambulance or go to the hospital no matter how sick I got. There were several times when I should have been there, but we were very afraid of what they would do and how they would treat us. Two times we know now, after obtaining copies of the labs, I was in metabolic acidosis and really needed to be seen in the ER. I nearly died both times.

No one should be so afraid to go to the hospital. No one should be afraid of doctors. No one should have to take their chances of staying home and hoping they won't die because they fear what the doctors will do to them. No one should fear going to the hospital because they will be given medications they should not have. No one should fear going to the hospital because they will be told they are mentally ill. No one should fear going to the hospital because they will be scoffed at. No one should fear going to the hospital because the doctors will not believe him or her. No one should be afraid to go to the hospital for fear the doctors will lie about him or her.

I know of many others who have Periodic Paralysis and are diagnosed and others who are not diagnosed, who have had similar experiences to mine. This is happening all over the world. They, like me, live in fear of ending up in the ER. This is just not acceptable. ER doctors need to be able to recognize and know how to treat Periodic Paralysis correctly. It is my hope that this website will finally shed some light on this rare syndrome for the doctors of the world.

I am now diagnosed, but still fear going to the ER and the hospital. However, I know now, that I don't really need to go unless my symptoms get serious. I am posting the following: "When to call an ambulance or go to the ER if you have Periodic Paralysis", from my previous article about Periodic Paralysis and the EMTs. This will help to alleviate some of the fears when one needs to call an ambulance or go to the ER.

Following that I am posting my outline plan to help others avoid the pitfalls of the emergency room.

When to call an ambulance or go to the ER if you have Periodic Paralysis

After studying Periodic Paralysis and Andersen-Tawil Syndrome, I have learned that an ambulance does not need to be called every time I become paralyzed. When I have an episode of paralysis, I will usually be fine in a few hours. However, if I have trouble with my breathing, my heart or with choking or swallowing, then an ambulance may be necessary.

Go to the emergency room or call the local emergency number (such as 911) if you faint or have difficulty breathing, speaking, or swallowing. These are emergency symptoms.

<http://www.nlm.nih.gov/medlineplus/ency/article/000312.htm>

In more serious cases, the swallowing or breathing muscles may be involved.

<http://www.activeforever.com/a-642-familial-periodic-paralysis.aspx>

When dealing with **hyperkalemia**, high levels of potassium, the following may be helpful. I have been told, if the level is 6.0 or more than emergency treatment may be necessary:

The following is a guideline for hyperkalemia:

***Hyperkalemia** is a medical condition of elevated bloodstream levels of potassium. While the normal blood potassium level is 3.5-5.0 mEq/L, mild hyperkalemia can be between 5.1-6.0, moderate between 6.1-7.0, and severe above 7.0. In an extreme case, hyperkalemia can be an emergency as the condition may lead to fatal effects.*

<http://hyperkalemia.net>

Go to the emergency room or call the local emergency number (such as 911) if you have symptoms of hyperkalemia. Emergency symptoms include:

Absent or weak heartbeat

Changes in breathing pattern

Loss of consciousness

Nausea

Weakness

<http://www.nlm.nih.gov/medlineplus/ency/article/001179.htm>

More serious symptoms of hyperkalemia include slow heartbeat and weak pulse. Severe hyperkalemia can result in fatal cardiac standstill (heart stoppage). <http://www.medicinenet.com/hyperkalemia/page2.htm>

Mild hyperventilation is a symptom of hyperkalemia due to metabolic acidosis. http://www.ehow.com/facts_5446075_hyperkalemia-symptoms.html

Symptoms of hyperkalemia include abnormalities in the behavior of the heart. Heart abnormalities of mild hyperkalemia (5.0 to 6.5 mM potassium) can be detected by an [electrocardiogram \(ECG or EKG\)](#). With severe hyperkalemia (over 8.0 mM potassium), the heart may beat at a dangerously rapid rate (fibrillation) or stop beating entirely ([cardiac arrest](#)). Patients with moderate or severe hyperkalemia may also develop nervous symptoms such as tingling of the skin, numbness of the hands or feet, weakness, or a flaccid **paralysis**, which is characteristic of both hyperkalemia and **hypokalemia** (low plasma potassium).

<http://www.healthline.com/galecontent/hyperkalemia#ixzz1Imk6qHHA>

When dealing with **hypokalemia**, high levels of potassium, the following may be helpful.

Mild hypokalemia is often without symptoms, although it may cause a small elevation of [blood pressure](#),^[2] and can occasionally provoke cardiac arrhythmias. Moderate hypokalemia, with serum potassium concentrations of 2.5-3 mEq/L, may cause muscular weakness, [myalgia](#), and muscle cramps (owing to disturbed function of the skeletal muscles), and constipation (from disturbed function of smooth muscles). With more severe hypokalemia, [flaccid paralysis](#) and [hyporeflexia](#) may result. There are reports of [rhabdomyolysis](#) occurring with profound hypokalemia with serum potassium levels less than 2 mEq/L. [Respiratory depression](#) from severe impairment of skeletal muscle function is found in many patients. Some electrocardiographic ([ECG](#)) findings associated with hypokalemia include flattened or inverted T waves, a [U wave](#), ST depression and a wide QT interval.

<http://en.wikipedia.org/wiki/Hypokalemia>

[Hypokalemia](#) is defined as a potassium level less than 3.5 mEq/L.

Moderate hypokalemia is a serum level of 2.5-3 mEq/L.

Severe hypokalemia is defined as a level less than 2.5 mEq/L.

<http://emedicine.medscape.com/article/767448-overview>

Cardiac arrhythmias This phrase is used to collect a group of different conditions where the heart has abnormal electrical activity. It does not mean that the heart beat is irregular, although it can be, it can also be regular. The speed of the heart beat may be either fast or slow as compared to normal. In some cases of cardiac arrhythmias, they can be medical emergencies and a life-threatening situation.

<http://www.hypokalemia.net/symptoms.php>

Avoiding the pitfalls of the emergency room

It is imperative for one with Periodic Paralysis to know the above information and to have this important information written and handy in case an ambulance must be called. I keep this information in a plastic folder along with everything I know is important and that the EMTs must know when coming to my aid in an emergency and for the doctors when I get to the hospital. I approach it as if I will have no one with me to explain my needs. I keep it near the door and take it with me when I leave home. The information you should have in your folder is found on page 6.

Since I received my diagnosis, due to the previous mishaps in the ER and the hospital, I have taken a trip to the hospital with all of my records. I had them copy all of my information. This is for four reasons. First, to prove my diagnosis; second, to teach the doctors about Periodic Paralysis; third, to educate the doctors so they will know how to treat me the next time I am in a crisis and fourth; to clarify all the lies and misdiagnoses.

While there, I explained that they have to monitor my breathing; make sure I don't choke and monitor my heart due to the tachycardia, and arrhythmias, watching especially for the long QT interval beat. They are not to hook me to an IV; not to give me glucose or any medications. They are not to use a tourniquet or have me make a fist if they need to take my blood. They should look through my file and/or folder for any other info they may need. It is also important for them to know listen to your significant other (if you are lucky enough to have one), who will be your voice, if you cannot speak or explain things to them.

Since that conversation, and now having everything in place for the next emergency, I feel better about the possibility of having to ride in an ambulance and being admitted to the hospital if needed in the future.

The following is my outline plan:

1. Call hospital administration office
 - a. Explain your problem
 - i. Tell them the history of visits and the problems during them
 - ii. Tell them about your fears due to the previous visits
 - iii. Explain your diagnosis or possible diagnosis
 - iv. Explain your plan to bring in all your records for your file
 - v. Ask how you can speak to the supervisor of the ER
2. Call the ER supervisor or make an appointment to meet with him/her
 - a. Explain your problem
 - i. Tell them the history of visits and the problems during them
 - ii. Tell them about your fears due to the previous visits
 - iii. Explain your diagnosis or possible diagnosis
 - iv. Explain your plan to bring in all your records for your file

3. Meet with ER supervisor or representative in person
 - a. Bring your significant other or a friend or family member
 - i. Present your records
 1. Name and numbers of your doctors
 2. Information about Periodic Paralysis
 - a. Copied from the internet
 - i. The types
 - ii. Andersen-Tawil Syndrome?
 - iii. Hypokalemic Periodic Paralysis?
 - iv. Hyperkalemic Periodic Paralysis?
 1. How to take your labs
 2. How to treat your symptoms
 3. How to diagnose, if not done yet
 3. Your diagnosis reports (from doctors) if you have them
 4. List of medications you can not have
 - a. No IVs
 - b. No medications that paralyze
 - c. No meds that cause long QT (if it applies)
 5. List of medications you take
 6. List of other medical issues
 - a. Possibly diabetes, heart problems, etc
 7. Records of previous labs and tests which helped with the diagnosis or ruled other things out to include but not limited to:
 - a. EKGs,
 - b. Holter monitors results
 - c. EMGs
 - d. EEGs
 - e. Muscle biopsy
 - f. Sleep studies
 - g. Pulmonary study
 - h. Physical therapy
 8. Letter from therapist clearing you of mental issues
 - a. Good to be seeing a therapist to help deal with
 - i. Failing health
 - ii. Moral support
 9. Possibly a standing prescription from your doctor:
 - a. “if muscle weakness or paralysis”
 - i. “Blood serum labs for Potassium”
 10. Have hospital records copied by:
 - a. Records department or
 - b. ER personnel
 11. Explain anything else you believe is important
 12. Always carry a plastic folder with copies of the above information in case you find yourself out of your local area in an emergency.

A serious article about hospital errors:

Hospital Errors May Occur In A *Third* Of Admissions

http://www.huffingtonpost.com/2011/04/07/hospital-errors-may-occur_n_846077.html

From:

[Successful hospitalization of patients with no discernible pathology](#) by Grant Innes MD:

(A little humor...mentions Periodic Paralysis)

How to admit your patient when you have no idea what's wrong with them

<http://www.impactnurse.com/?p=470>