

**Periodic Paralysis and the EMTs**  
**“NO IV OR TOURNIQUET PLEASE”**  
**By Susan Q. Knittle-Hunter**

On three different occasions I rode in an ambulance to the hospital due to symptoms of Periodic Paralysis, however, at the time I had no idea what was wrong. It was very frightening. Calvin and I assumed the problem was my heart because of the tachycardia and chest pain involved. On one of the occasions, total paralysis was also involved as well as muscle contractions throughout my body that made it look like seizures. During that trip, one of the EMTs gave me some glucose by mouth. He told me I was hypoglycemic. Within a few minutes, my body was jerking, 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.

On the other two trips I did not get the glucose. The ambulance was called due to total paralysis and tachycardia. On all three occasions, I was hooked up with an IV as I lay in the ambulance in the driveway. We sat there for quite awhile before we left for the hospital. It was a long, slow drive to the hospital because we lived in the mountains about 10 miles outside of town. I arrived at the hospital in worse condition than when I left my home. It was not until I realized I had Periodic Paralysis and began to study everything I could about the condition that I discovered why this happened.

I should never have been given IV's of glucose, dextrose or saline. Apparently, the IVs had worsened my condition on each occasion. The following passages discuss this issue:

*Intravenous potassium should be avoided whenever possible; however, if it is indicated for arrhythmia due to hypokalemia or airway compromise due to ictal dysphagia or accessory respiratory muscle paralysis. Mannitol (which is inert) should be used as the solvent (rather than saline or dextrose, which are both potential triggers of attacks) [5].*  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2374768/>

**IVFluids**

*Only as needed to administer IV KCL in mannitol or normal saline (5% glucose IV may worsen situation) or IV propranolol (see below) (1,4,10)[C]*

[http://im.unboundmedicine.com/medicine/ub/view/5-Minute-Clinical-Consult/116308/all/Hypokalemic\\_Periodic\\_Paralysis](http://im.unboundmedicine.com/medicine/ub/view/5-Minute-Clinical-Consult/116308/all/Hypokalemic_Periodic_Paralysis)

*Because of the rarity of the condition, perinatal experience with FHPP is limited (14,15). General anesthesia, postoperative stress, glucose-containing IV solutions, and long-acting neuromuscular blockers are associated with postoperative paralytic episodes.*

<http://www.anesthesia-analgesia.org/content/88/5/1081.full>

*Glucose-containing intravenous fluids should not be used in patients with hypokalemic paralysis, whereas such solutions may benefit patients with hyperkalemic and normokalemic paralysis (see above).*

<http://www.accessanesthesiology.com/abstract/894234>

*Mannitol (which is inert) should be used as the solvent (rather than saline or dextrose, which are both potential triggers of attacks) [5].*

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2374768/>

*No D5 in i.v. fluids. If possible, no saline in fluids – may try mannitol 5% to give bolus of potassium.*

<http://www.periodicparalysis.org/english/view.asp?x=526&all=true>

**DO NOT:** administer I.V. dextrose or saline (as these are potential **triggers** for periodic **paralysis**) unless indicated for supervening medical conditions

*If intravenous fluids are necessary, understand that the glucose in D5W and the sodium in ½ NS can **worsen hypokalemia** in hypokalemic periodic paralysis*

<http://www.periodicparalysis.org/CMFiles/EMS%20Orientation.pdf>

Besides the important information about IVs, it is also important to understand that improper use of a tourniquet and the clenching of the fist can result in false lab results for potassium levels. The pressure (too tight) and time (too long) of the tourniquet can raise the level of potassium. The following articles explain this problem.

*"Pseudohyperkalemia is typically caused by hemolysis during venipuncture (by either excessive vacuum of the blood draw or by a collection needle that is of too fine a gauge); excessive tourniquet time or fist clenching during phlebotomy (which presumably leads to efflux of potassium from the muscle cells into the bloodstream);[4] or by a delay in the processing of the blood specimen."*

<http://en.wikipedia.org/wiki/Hyperkalemia#Pseudohyperkalemia>

*"Pseudohyperkalemia Caused by Fist Clenching during Phlebotomy"*

<http://www.nejm.org/action/showImage?doi=10.1056/NEJM199005033221806&iid=f00>

[1](#)

<http://www.nejm.org/doi/full/10.1056/NEJM199005033221806>

<http://www.ncbi.nlm.nih.gov/pubmed/2325722>

<http://en.wikipedia.org/wiki/Hyperkalemia#Pseudohyperkalemia>

*"Excessive tourniquet time, too tight tourniquet or fist clenching during phlebotomy (which presumably leads to efflux of potassium from the muscle cells into the bloodstream) are other important cause of fictitious hyperkalemia."*

<http://www.ijccm.org/article.asp?issn=0972-5229;year=2007;volume=11;issue=4;spage=215;epage=217;aulast=Sharma>

*But I guess we should ask first "When have you calibrated pressure gauge of the tourniquet?" (unless the nurse tend to lose temper...)*  
[http://www.tourniquets.org/use\\_care.php#calibrating\\_testing](http://www.tourniquets.org/use_care.php#calibrating_testing)

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. 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 are found on page 6.

Due to the previous mishaps, I have taken time to call my ambulance company and explained my condition to them, so they will understand ahead of time and be ready to assist me appropriately. At first, the person I talked to began to laugh at me and scoff about my calling with information ahead of time. She said it wasn't necessary for them to know anything before the ambulance is called. I began to cry in frustration and told her that she could laugh and scoff if she wanted to, but she had better pay attention to what I was saying. I told her I had a very rare disease that only 100 people worldwide have been diagnosed with, and I had some very serious health issues that required special attention. I told her if I was not treated appropriately, I could die.

She got very quiet and serious and then began to ask me questions. After listening to my answers and the other information I offered, she told me she would have a meeting with the EMTs and train them about Periodic Paralysis: Andersen-Tawil Syndrome and my special needs and what to do when they get a call to help me. I told her to instruct them to look at my file and listen to my husband's instructions. He will know my potassium levels (we have a cardy meter) and they had to trust what he says.

I explained that they have to monitor my breathing; make sure I don't choke and monitor my heart due to the tachycardia, and arrhythmia's, 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 the folder for any other info they may need before reaching the hospital.

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 in the future. Now that I am ready to call an ambulance, I need to know when to call an ambulance. The following should be helpful.

## When to call an ambulance 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](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**, low levels of potassium, the following may be helpful.

*Mild hypokalemia is often without symptoms, although it may cause a small elevation of [blood pressure](#),<sup>[2]</sup> 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>

In my folder I have the following items:

1. A card with the names and phone numbers of my doctors
  2. A list of medications I cannot have.
  3. Information copied from the internet explaining Periodic Paralysis: Andersen-Tawil Syndrome
  4. Information on how to treat, hypokalemia and hyperkalemia since I have both
  5. Information about long QT interval heartbeat
  6. A letter from my therapist explaining that I do not have a mental illness
  7. The documents with my doctors' diagnoses of PP:ATS
  8. A list of my other diagnosed conditions, ie diabetes, osteoporosis, restless leg syndrome
  9. A card similar to the one below provided by the PPA: (No need to re-invent the wheel)
- <http://www.periodicparalysis.org/CMFiles/PPA-EmergencyInformation-B.pdf>

## Emergency Information

Patient Name: \_\_\_\_\_

In Case of emergency call: \_\_\_\_\_

I have: \_\_\_\_\_

My doctor is: \_\_\_\_\_

MD Tel: \_\_\_\_\_

Allergies: \_\_\_\_\_

Medications: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Medical Problems: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

To Abort My Attacks, I usually: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

The Periodic Paralysis (PP's) are inherited muscle membrane disorders characterized by episodic weakness and paralysis. PP's are classified as hypo- or hyperkalemic but serum K<sup>+</sup> may never range outside the norm. Paralysis may be localized or generalized but can extend to facial, bulbar and respiratory muscles and can be fatal. Consciousness and sensation is preserved even during profound paralysis. Handle unresponsive patients with due care. Episode triggers depend on the PP variant. Therapy for acute attacks requires serum potassium manipulation. Chronic treatment includes diuretics (e.g., acetazolamide and potassium sparing agents for hypoPP, and acetazolamide or potassium wasting agents for hyperPP), dietary management, and potassium supplementation (for hypoPP).

Andersen-Tawil Syndrome involves PP and cardiac arrhythmia, specifically a long QT interval and risk for ventricular tachycardia.

<http://www.periodicparalysis.org>

### Hypokalemic Periodic Paralysis

Flaccid paralysis of varying severity occurs with rest after exercise, high carbohydrate meals, large meals, salty foods, cold, or epinephrine.

Paralysis is associated with a fall in serum potassium.

Attacks of complete paralysis can last hours. Cardiac Signs: Sinus bradycardia and EKG signs of hypokalemia. Watch for prolongation

of the PR and QT intervals. Hypokalemia should be treated by oral potassium supplementation if possible (0.5-1.0mEq/kg). If use of i.v. KCl is unavoidable, use K<sup>+</sup> in Mannitol (5% mannitol solution with 5mEq KCl/L) to terminate a paralytic attack: 15 mEq [15mmol] over 15 minutes, then 10 mEq/hr [10mmol/hr]. Avoid saline or glucose.

The diluents (both glucose and NaCl) typically used for IV administration of K<sup>+</sup> invariably result in an immediate and potentially hazardous decline in blood K<sup>+</sup>. An alternative is to give small boluses, 5mEq/bolus, in Lactated Ringers .

### Hyperkalemic Periodic Paralysis

Flaccid paralysis of varying severity occurs with rest after exercise, potassium ingestion, or cold. With paralysis comes an increase in serum K<sup>+</sup>. Severe attacks may persist for several hours. Attacks may be accompanied by myotonia and arrhythmias. EKG may reveal hyperkalemia (peaked T waves, QRS widens, P wave flattens). Use candy bar or inhaled albuterol to abort an attack. Slow infusion (over 5 min) of 10% calcium gluconate reduces cardiac sensitivity to hyperkalemia.