

How Do I Discover My Triggers? **“IF YOU DID NOT WRITE IT DOWN, IT DID NOT HAPPEN”**

By Susan Q. Knittle-Hunter

One of the most important things we can do as people with Periodic Paralysis (PP), no matter what type we have, is to figure out what causes, starts or triggers our episodes of weakness or paralysis. This is important because we need to stop the episodes, if possible, in order to regain the quality of our lives and to prevent the damage being done to our organs as the potassium shifts and depletes in our bodies. This damage can lead to permanent weakness and disability.

In the case of people with Andersen-Tawil Syndrome, the paralysis leads to tachycardia and serious arrhythmias, including long QT intervals, which can lead to cardiac arrest. Avoiding paralysis is absolutely necessary, due to these life-threatening effects.

From my research, I find the latest literature indicates certain foods, medications, conditions and activities can trigger most the paralysis events. The easiest way to decide what caused an episode would be to look at anything new or different....a new type of bread, a new antibiotic, a new activity, a new shampoo, stressful event, or a heated room.

If it is not that easy to figure out no, we can discover what they are, if we take a little time to follow a simple plan. In a matter of a few days or weeks, it may be possible to gain some useful conclusions about the possible triggers of a paralytic event.

In the field of medicine and in education, it is said, “If you did not write it down, it did not happen”. This can be applied to our method for discovering our triggers. The first thing we must do is to write everything down. I have created a **chart** to make the process easier.

Several necessary components are included on this chart:

A 24hour time frame

A section to write possible triggers

A section to write down symptoms one may be feeling

A section to record the muscle weakness and paralysis

This section becomes a graph of the periods of weakness or paralysis

Once the information has been gathered for a few weeks, it will be easy to see trends or connections of a particular food, medication or activity to muscle weakness or paralysis.

Next, we need to know what the more common triggers are for PP attacks. The following is a list I have compiled from several sources:

Diet: Our diet can be one of the biggest contributors to episodes of paralysis.

Simple carbohydrates: sugar, white flour, etc.

Complex carbohydrates: Some grains ie, wheat, etc.

Meat: Mostly red meats,

Salt

Caffeine

MSG

Alcohol

Large Meals

Sleep: All aspects of sleep have set my episodes into motion :

Falling asleep

During sleep

Waking up

Stress (Good)

Stress (Bad)

Dehydration

Fasting

Sitting too long

Changes in the weather

Fatigue

Heat

Cold

EMFs

Exercise: Episodes may develop soon after or the next day.

Rest after exercise: may set an episode into motion.

Medications

Saline Drips

Glucose Infusion: If an IV is needed, Mannitol can be used

Oral or Intravenous

Corticosteroids

Muscle Relaxers

Beta Blockers

Tranquilizers

Pain Killers (analgesics)

Antihistamines

Puffers for Asthma

Antibiotics

Eye Drops to Dilate Eyes

Contrast Dye for MRI's

Lidocaine

Anesthetics

Epinephrine

Adrenaline

Over-the-counter medications:

Cough Syrups

Eye Drops

NSAIDs

If the following ingredients are in any products you use...you should stop using them until you are sure they are not causing symptoms:

Sodium Hydroxide

Edetate Disodium

Stearic Acid

They may be in any of the following:

Lotions

Oils

Hair dyes or colors

Antiperspirants

Enemas

Suppositories

Soaps

Shampoos

Shaving creams, foams

Toothpastes

Deodorants

Beauty products

Skincare products

Cosmetic products

Bath Salts

Emollients, Ointments, Creams

Hair sprays

Perfumes, colognes

Powders

Hair gels, oils, tonics, mousse

Unknown: I can follow all the rules and still have episodes for unknown reasons.

Understanding and becoming familiar with the symptoms is another important part of completing the chart. As much information as you can add will be helpful. In this section anything may be included from “**feeling well**”, or “**none**”, to the following known symptoms for hyperkalemia and hypokalemia:

Hyperkalemia

Muscle weakness
Muscle cramps
Fasciculations
Tightness in legs
Strange feeling in legs
Tingling sensations
Paralysis, partial
Paralysis, total
Pulse issues - absent, slow, or weak
Heart palpitations
Irregular heartbeat
Breathing problems – fast breathing
Mild hyperventilation
Nausea
Feeling hot
Slurring words
Sleepiness
Confusion
Memory problem
Depression
Malaise

Hypokalemia

Muscle weakness
Muscle stiffness
Muscle aches
Muscle cramps
Pins and needles sensation
Paralysis, partial
Paralysis, total
Tachycardia –fast heart beat
Irregular heartbeat
Breathing problems -barely breathing
Hypoventilation
Irritability
Severe thirst
Nausea
Vomiting
Constipation
Excessive urination
Sweating
Spacey
Tiredness
Rise in blood pressure
Hyporeflexia

The following are more possible symptoms to choose from for the chart:

Headache,
Chest pain,
Numbness,
Unable to walk,
Slurred speech,
Shallow breathing,
Pain in calves,
Cramps in legs,
Restless legs,
Burning in feet,
Tightness in leg muscles,
Feeling cold,
Clammy,
Dizzy,
Shaky,

Unsteady,
Rubbery legs,
Hungry,
Jerking,
Awake,
Confusion,
Strange feeling in legs
Sleepiness
Sleeplessness
Memory problem
Depression
Weakness
Breathing problems
Constipation
Pins and needles sensation

We are now ready to complete the Trigger Chart:

1. Fill in the date
2. Begin recording your activities, food, drink and medications in the top section. Start at the time you wake up. Include all food eaten in a meal. Record what you are doing, i.e., sitting, eating, reading, exercising, walking, cooking, shopping, etc.
3. Record how you are feeling, i.e., good, very thirsty, constipated, confusion, sleepy, unsteady, legs are weak, total paralysis, etc.
4. Put a check mark in, (or fill in) the box that best describes your condition, i.e., normal, weak, more weak, partial paralysis, more partial paralysis, or total paralysis.
5. Continue this through your day, it is not necessary to do it at night, but you may want to include paralysis, numbness, etc., if it is happening at night.
6. The bottom of the chart will become a graph and it will aid in seeing the times of symptoms.

In the completed chart below, we can see that 2 ½ to 3 hours after eating breakfast and taking sepra, an antibiotic and a calcium tablet, the patient begins to go into weakness and then paralysis. **It is a good chance that the medication or something eaten at breakfast was the cause.**

If this person eats the same thing everyday and takes the calcium every morning, and **the only new thing is the sepra it would be safe to assume the antibiotic caused the episode.**

By 4pm the episode has stopped. At 5pm weakness begins after an hour of being up and preparing dinner. **This may be from exercise intolerance or due to something eaten at lunch.**

If the person eats the same lunch everyday but doesn't always help with dinner, **it could be safe to assume the exercise caused the weakness. The same could be true in reverse.**

At 7pm, overall weakness takes hold for the remainder of the evening. **This may be from the food eaten at dinner or a continuation of the weakness from the earlier activity.**

During the night there are 3 episodes of total paralysis. **Since sleep is a trigger, it may be impossible to stop the episodes throughout the night.**

.

1. When looking at your completed charts, it is best to first check the periods of paralysis. Then check the activity, medications taken or food eaten 2 to 3 hours before that time. Was anything new? Was any activity out of the ordinary?

1. Check period of paralysis or weakness:
 - a. Check 2 to 3 hours before
 - i. New medication?
 - ii. New food, drink?
 - iii. New activity?
 1. More than usual?
 2. Longer than usual?
2. If answer is not clear: Continue to chart for a few days. If there seems to be a pattern:
 - a. Change only one thing at that time:
 - i. Remove sugar or
 - ii. Cut medication dose or
 - iii. Stop or reduce the activity
 1. Less than usual
 2. Shorter than usual
3. Check again after a day or two. If the symptoms of paralysis are reduced or better, you may have found the trigger.
If not, add the thing you removed or reduced back into the meal, etc.
Then repeat 2 and change something else:
 - a. Change only one thing at that time:
 - i. Remove sugar or
 - ii. Cut medication dose or
 - iii. Stop or reduce the activity
 1. Less than usual
 2. Shorter than usual
4. Repeat until you find the trigger or triggers.

Some suggestions for how to avoid the triggers once they are found:

On feet too long? : Break the activity in several shorter periods on feet.

Cannot eat sugar? : Stop and try sweeteners, honey, stevia, etc.

Cannot eat certain food? : Find replacement or do without.

Cannot take medication? : Cut dosage, stop taking or get a replacement.

Sitting too long? : Get up every hour or less and move around.

Sitting too long? : Exercise in chair.

Dehydrated? : Drink more water, set timer.

Hungry? : Eat several smaller meals.

Too hot? : Wear looser, cooler clothes, use neck cooler.

Too cold? : Add clothing layers, use a blanket, drink hot drinks

Cannot drink caffeine: Buy decaffeinated drinks,

Trigger Chart

Time	Activity	Symptoms	10:00am	11:00am	12:00pm	1:00pm	2:00pm	3:00pm	4:00pm	5:00pm	6:00pm	7:00pm	8:00pm	9:00pm	10:00pm	11:00pm	12:00am	1:00am	2:00am	3:00am	4:00am	5:00am		
6:00am	Public, get up, Bathroom	Legs weak																						
6:30am	Shower, Dress																							
7:00am	Breakfast: sugar milk	Legs and below feet																						
7:30am	Egg, toast, egg, almonds																							
8:00am	Take sugar, cotton tank	None																						
8:30am	Make bed, clean kitchen	None																						
9:00am	In kitchen																							
9:30am	On computer	Feeling tired, warm, hot																						
10:00am																								
10:30am																								
11:00am																								
11:30am																								
12:00pm																								
12:30pm																								
1:00pm																								
1:30pm																								
2:00pm																								
2:30pm																								
3:00pm																								
3:30pm																								
4:00pm																								
4:30pm																								
5:00pm																								
5:30pm																								
6:00pm																								
6:30pm																								
7:00pm																								
7:30pm																								
8:00pm																								
8:30pm																								
9:00pm																								
9:30pm																								
10:00pm																								
10:30pm																								
11:00pm																								
11:30pm																								
12:00am																								
12:30am																								
1:00am																								
1:30am																								
2:00am																								
2:30am																								
3:00am																								
3:30am																								
4:00am																								
4:30am																								
5:00am																								
5:30am																								
6:00am																								

Symptoms
 Conditions
 1. Paralytic
 2. Pain
 3. Weakness
 4. Fatigue
 5. Headache
 6. Nausea
 7. Dizziness
 8. Blurred vision
 9. Tinnitus
 10. Loss of consciousness

