



Registered Charity No: 1108016

FEATURE ARTICLE: STATUS EPILEPTICUS

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Contents approved by: Professor Helen Cross - Matthew's Friends Medical Board.

Meeting: Epilepsy Specialist Nurses conference Nottingham May 2010

Subject: Professor Matthew Walker talked about the management of status epilepticus.

Around half of first seizures are status.

If status has occurred once it is more likely in those people to reoccur.

Status caused by weaning medication usually has a good outcome.

The quicker the seizure or cycle of seizures is stopped the better, the longer it continues the harder it is to stop.

Many use benzodiazepine medication at home as emergency meds. These should be given as quickly as possible. The first dose takes 30 mins to fully impact it then has a 30 hour elimination time. Further doses may not be as effective as once the fat and muscle is saturated it cannot process more benzos to stop the seizure, it then has nowhere to go and that's when it can build up and cause respiratory arrest. You should be given a limit by your neurologist for the amount given at home in a 24 hours period.

IV Lorazepam is the first line of treatment in hospital; Paraldehyde is sometimes used successfully (not by Professor Walker, he works with adults) then IV Phenytoin or Phenobarbitone is usually used.

The body compensates around the seizure, maintaining blood supply to vital organs and keeping blood pressure up. IV fluids should be started as soon as possible because the body will become more acidic this is particularly important for our keto kids!

There is a window of between approximately ½ an hour to 2 hours depending on age and strength of the person, then the body stops compensating, blood

pressure drops, the heart rhythm will be affected, organs will start to fail and brain damage will happen, this is when anaesthetising is the only option to avoid that damage. Usually medication is needed to bring the blood pressure up and make sure the pressure is high enough to keep the kidneys functioning. Professor Walker also advised that EEG should be checked incase underlying seizure activity is still going on.

Apparently there are some hospitals that don't even have protocols for status, which makes it even more important to work out a set protocol with your neurologist to give to your local hospital, ambulance service, GP and also have your own copy (which you could have signed by your neurologist and keep in your keto file).

One thing that particularly horrified me was that in our area a car is sent out on calling 999, (which you can wait a while for) THEN they decide if an ambulance is required. Paramedics only seem to carry tiny doses of diazepam and when you have already given all you can its irrelevant anyway. We wrote to the head of the ambulance service to make sure that an ambulance is sent from now on so we miss out the first stage of having a car/bike come to 'assess' first. We just had to get Greg's neurologist to send a letter to confirm the need. I also have to remember to renew the agreement every six months. Something else to add to our long list of what we need to do!

If your child is prone to Status then we would recommend the following:

1. Work out an emergency protocol with your neurologist and get it signed off by them (there is a draft form to complete in your MF Keto Files) – make sure it is updated at least once a year with your neurologist.

Send it to:

Local Hospital A&E Dept
Local Hospital Consultant
GP
Ambulance Services
Carers/Respite Services
School
Copy in Keto File.

2. Discuss and work out an emergency protocol with your Dietitian to use if your child is in hospital following treatment for status (or any hospital admission for that matter). Please remember that the most important thing is to deal with the status FIRST. Again any emergency protocol should be placed in your keto file and also sent to the local hospital/GP