Recording of data

I have previously referred to the analogy of the Flight Director on Apollo 13 and his comments after the oxygen tank exploded. This was not in the flight plan. As an aside it had nothing to do with the unfortunate crew, rather it was a design issue which had not been addressed in the previous years to the actually flight. It was an accident waiting to happen. I digress. I paraphrase his comments:

'Let's view this from a position of status. What have we got that's good'. Later he then says 'I want to know what it (**sic**) can do. Not what it was designed for or built to do'.

I record data on myself. I use a Memento database on my phone. Android. I have created a simple library where I record the following. The categories relate to me, the data I want to record and so may not be appropriate for generalised use. I am happy to share my very simple dataset with others if people want to look at how I have set it up. Email the link on the hompegae.

- Date & Time
- Duration of sequence. I may have multiple seizures within a sequence
- Number of seizures within sequence
- Seizure type. I record these a physical (full body seizure), non-physical (absence or those where I freeze and cannot move or talk) and distracted. I have started to record distracted from 1st July with an intent. This is to 'convert' the physical into distracted. I record how I distracted the event. Yes, I am using the terminology of conversion against itself, I am converting physical seizures into distracted seizures. The cunning plan is revealed
- Type of event. I record the characteristics of the seizure. For example, left tremor, left right tremor, violent. These are tick boxes so that I can record all of the characteristics
- After status. I record how I am after the event. For example, headache, speech impairment, lucid, slow to recover.

What this has allowed me to do is build my own profile of when I seize. Seize what. I have a seizure. This is then aggregated by day, month and then within hour. The latter is important so that I can start to see if there are cluster times. I can then look back and see what I was doing in both general terms during these times of the day and specifically correlate to my notes I write each day to determine if there are very specific triggers. For me, sensory overloads are of particular noteworthiness as well as very bright lights and transition from darkness to light and vice versa.

So, to some data. You will see examples of these contained within my posts.

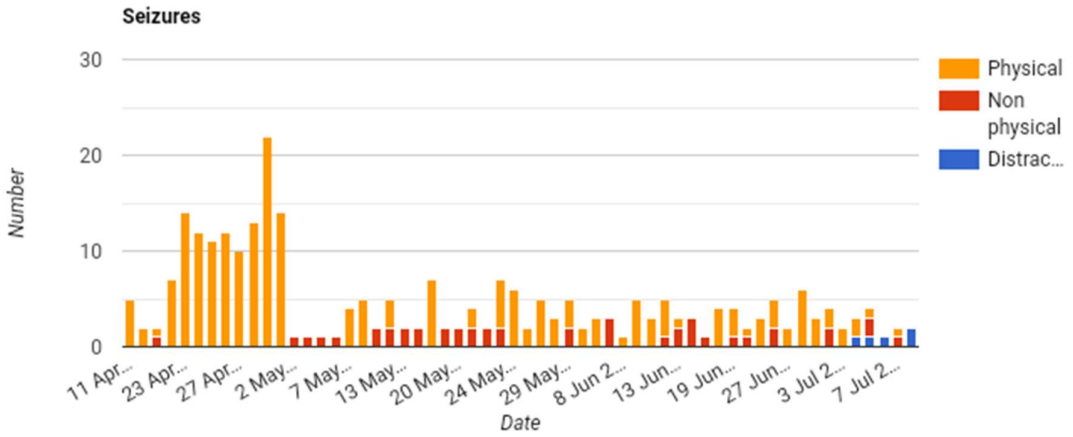
Before you look at the data so points to consider.

I have two types of seizures see the section on 'understanding more about how to manage the types of seizures' for a fuller description.

When I first started to record the data in April, I did not differentiate between physical and non-physical nor did I record the non-physical. I was still learning. Thus, April is an incomplete data set but allowed me to start.

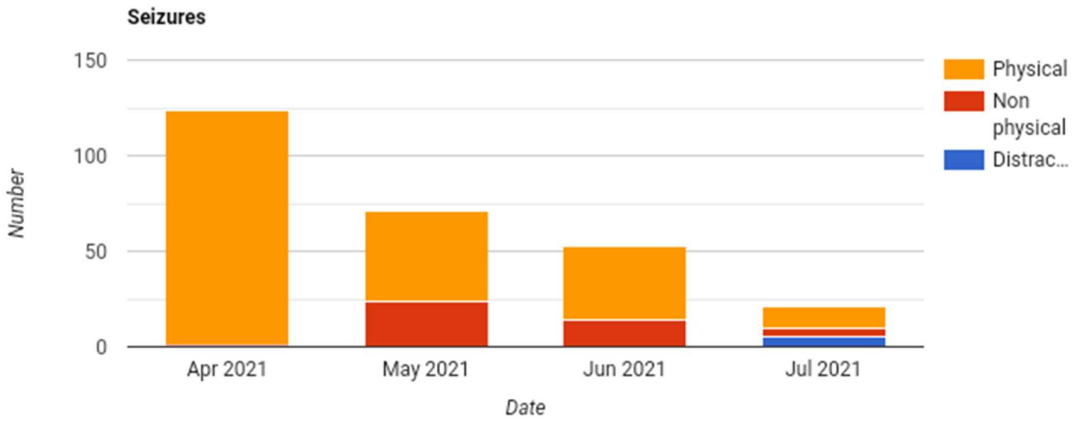
I also maintain a daily diary where I write down how the day has been. Notable events. How I feel. How have others felt. It is a truism that we can pass on to each other 'emotions' both verbally and by our respective body language. A commentary on the seizures I have had and events before and after. This allows me to correlate seizure activity and what I was doing so that I might get a better understanding of either the environment or triggers which result in a seizure sequence. After all, that is what we want to do. Namely, manage and control the seizure events. I describe this as what colour of socks was I wearing (aka environmental factors).

Seizure activity by day.



This is just the days events. What is interesting to note here, is the left to right transition. On the far left you will see lots of seizure activity. This is when I was in hospital. If anyone needs to know why it is a very bad idea indeed to be in hospital, just look at the increase after 23 April when I was admitted to hospital for the second time. The peak is the day I came home from hospital, when I was coming to terms with 'everything' and had an awful lot of family around. Well, it is true to say, the sensory overload was extreme. The number of seizures in hospital is notable compared with being at home and the difference it makes not being in hospital. This is the real evidence that once diagnosed being discharged immediately makes a huge difference. The reality is that for anyone, being in, or even just visiting hospital is not a good place to be. It is an 'unnatural' environment and we all have the learned response that being in hospital means that there is something not right. Hence, just being there exacerbates any underlying condition. You can test this yourself. Take a blood pressure reading at home. Note the values. Then go and see your GP. Wait in reception. Go into the consulting room and ask them to take your blood pressure. You will see a difference. Now, as you have all the time in the world, make an appointment to see a specialist in any discipline in an acute hospital. Plan your day, pack your sandwiches and attend. When your number is called and you move from the vast atrium of waiting rooms to a room to see your nominated specialist, ask them to take your blood pressure. You will notice a difference. A simple test but now consider that this is a measure of the 'affect' and your learned response. To further amplify this, then spend time in hospital when you have been taken there for investigation and no-one knows the cause and you are in the process of differential diagnosis. The general 'stress' and I use that word in its broadest sense, is acute. Maybe we should rename acute hospitals to acute stress environments as that in reality is the impact it has on most people, and I generalise.

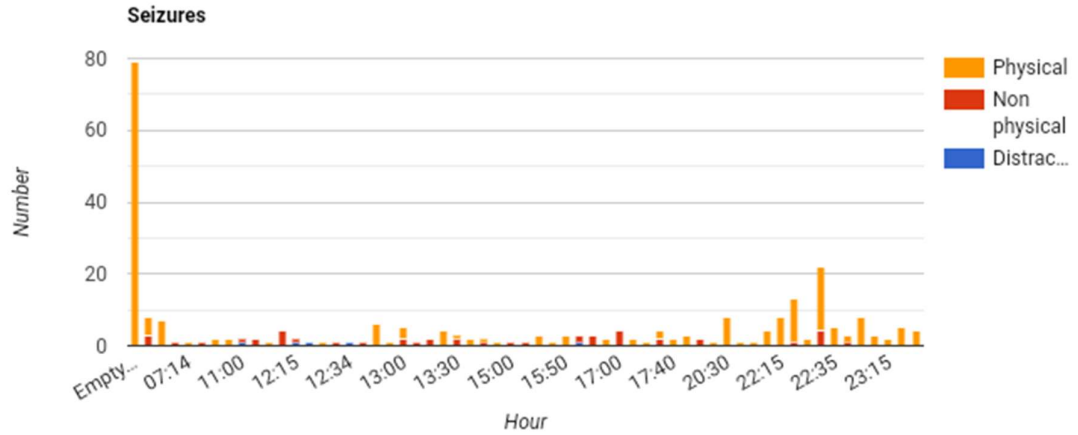
Seizure activity by month.



This is the same data aggregated into calendar months. This allows me to track my progress against the categories. It also allows me to have a positive feedback loop where I can demonstrably see, what has been the impact of the changes I am making. This is really important to reinforce the new neural pathways learnt. You can objectively see the difference.

This shows the impact of me accepting and moving quickly to adopt practical techniques and strategies as the way forward. Acceptance is key. I refer you to my posts about the combination of acceptance and being comfortable with 'doubt and uncertainty' linked to positive outcomes.

Seizure activity by hour.



This is where it starts to become very interesting indeed. For me, this has allowed me to be able to start to identify those times of the day where I am at a greater probability of having a seizure sequence. The emphasis is upon probability as one of the key features of NEAD is its perceived variability of event manifestation.

When looking at this chart it is important to note that the events recorded under 'empty' at the far left, relate to the time I was in hospital and have therefore been excluded from the time

distribution. The reason for this is that being in hospital is an ‘unnatural’ environment and so are statistically invalid for the purposes of distribution analysis.

The data is starting to show clustering into four ‘time zones’.

- between 1300 and 1400. I am now starting to focus on this time period to more fully understand what I am doing in this period and identifying specific trigger events and events prior which may contribute;
- between 1700 and 1830; I am now starting to focus on this time period to more fully understand what I am doing in this period and identifying specific trigger events and events prior which may contribute;
- between 2215 and 2330. This is one that I am actually very comfortable with. Why. Well, this is the period of transition from wakefulness to sleep. The literature points to many physical seizures occurring during ‘resting’ states. To my mind, this cluster sequence is where the brain is transitioning itself from one state to another and is more prone to be allow a seizure sequence to begin. This is due to the natural process of moving from voluntary to involuntary. From conscious to sub conscious and the key trait of NEAD is it is an involuntary action. You would therefore expect seizure events to be more likely to happen during this transitionary state. I am also comfortable with this as if a spart of everyday life, you say to yourself. Well, its time for bed. Let me clean my teeth, go to the toilet and have a couple of seizures, well hey ho, I can live with that. The seizures are contained within a very limited time frame, I am in a safe place, typically lying down and well what else would I be doing anyway. Its seems to me to be quite a reasonable trade off to have a couple of seizures in this period rather than other times where they may be more disruptive to life. Just my take on it;
- there is then the final cluster. Note that these are not included in the above distribution as they happen when I am ‘asleep’. I have not yet developed the skills to record data whilst being asleep and these are observations from my wife. These are overnight when I am asleep. These are more jerky, spasm like which tend not to develop into a physical seizure. These are probable related to REM sleep which is another topic entirely so are mentioned, but do not readily fall into the other three cluster types as they are probably from a different neural process.

So that is the data analysis so far. No doubt it will change over time but now I have some base data to work with.

Now what’s next.

‘I want to know what it (**sic**) can do. Not what it was designed for or built to do’.

And I shall end there, as the answer is clear. Neuroplasticity is key and the way forward.