

A FITFUL LIFE

CHAPTER 1

You've bought this book because you are interested in epilepsy, you may be a sociology/medical/psychology etc, student wanting to gain a greater insight into the psychosocial impact that epilepsy has on one's life, you may have learned of a family member or a friend who has been diagnosed with epilepsy and wish to know what the future looks like for them, you may have been diagnosed as having epilepsy; and wish to learn about how your disability will affect you and what precautions you may wish to take to minimise the possible disabling effects that epilepsy can have on your life; you may have noticed that this book also concerns the self- management of anxiety and depression which you may have been diagnosed as having and would rather self - manage than be on psychotropic medication, or you may have another of the many reasons for buying this book.

As this book is primarily about the life of someone living with epilepsy co-existing with anxiety and depression, the first thing you will wish to know is: "What is that condition that makes someone go unconscious, collapse and suddenly start shaking very violently?". One question you most likely won't be asking is: "What neurological disorder is making that man look very drunk and behave in a very bizarre way?", nor will you be asking: "What neurological disorder caused that man on the same train as me to suddenly start screaming out loud, shouting all types of offensive statements/ words, terrifying everyone around him, resulting in the British Transport Police placing him under arrest upon arriving at our destination?". One thing I could be confident with is that you would know the word 'epilepsy' to be part of the answer to one of these three questioned scenarios. I could also be confident that if you are a layman reading, you would most likely not know nor even consider the word 'epilepsy' to be part of the answer to the other two questioned scenarios. I could also be confident that when those that can identify epilepsy as being behind the cause of each of these three questioned scenarios are asked what epilepsy is, those asked would either not be able to explain at all; or would at best give a very unsure, unclear and most likely very inaccurate definition.

So what is epilepsy? The first thing that one must clarify is that it is not a mental health condition. Many people struggle to either tell the difference between, or appreciate the difference between a condition of 'brain'; and one of 'mind'. Epilepsy is a condition that affects the brain and not the mind. Epilepsy is what we call a 'neurological disability'. A doctor called a 'neurologist' treats this condition where as a doctor called a 'psychiatrist' treats a person with a 'mind condition' such as: schizophrenia, depression, anxiety etc. Many do question whether schizophrenia is a mind condition or a brain condition. Many conditions that affect state of consciousness were at one time believed to be conditions of mind in the days where little, if any, of the biology of these conditions was understood. This is why many conditions that were once treated by psychiatrists are now treated by neurologists. Such an example of a condition that was first believed to be a mind condition but has proven to be a brain condition as we have learned more about the biology of the condition is epilepsy. Many expect depressive disorders such as 'bipolar disorder', and other conditions that are still treated by mental health professionals e.g. schizophrenia, will eventually prove to be conditions of the nervous system as more is discovered about the biology of these conditions. There are already theories, such as bipolar depressive disorder being caused by fluctuations in levels of different neurotransmitters in the central nervous system; that are chemical messengers that are responsible for the creation of electrical energy in the brain. Such theories would evidence that bipolar

depressive disorder is caused by an imbalance in one's brain chemistry, making it a condition of brain and not of mind. Therefore, those who are being treated by psychiatrists today for having a condition such as bipolar depressive disorder, could find themselves being treated by neurologists tomorrow. In other words, bipolar depressive disorder, obsessive compulsive disorder and other, could end up following the same route that epilepsy took; which began in the field of psychiatry, ending up in the field of neurology; as doctors and scientists became more informed.

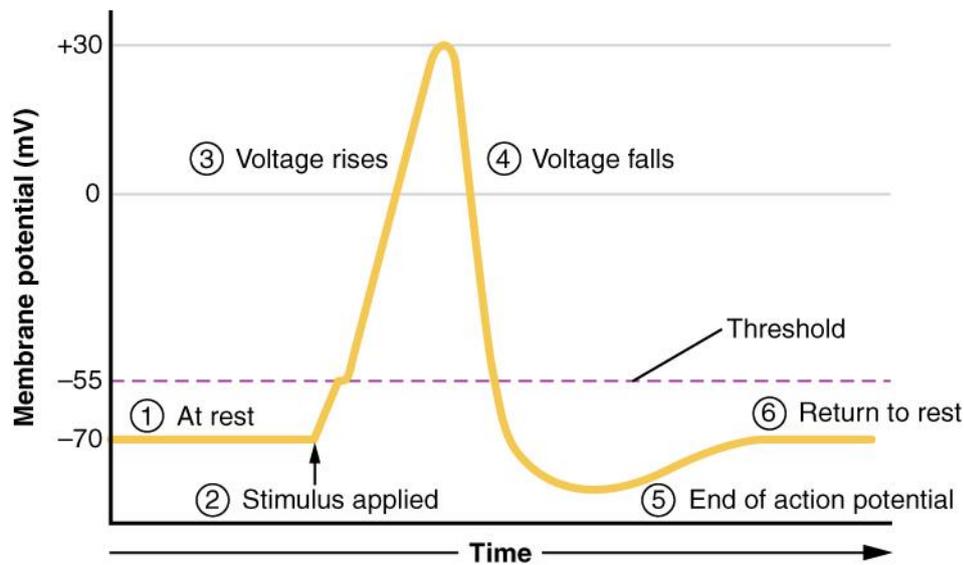
Epilepsy is a complicated condition, but a simple condition at the same time. Epilepsy is biologically simple, but politically and culturally very complicated. As someone who has lived with epilepsy since the age of three, I have compared notes of what living with epilepsy is like with people living with other neurological conditions such as multiple sclerosis. One thing I am told consistently by those affected by multiple sclerosis, parkinson's disease, stroke, motor neurone disease, spinal injury etc is that living with epilepsy is much more of a political/socio-cultural battle than it is a medical battle. It's more society's reception towards our disability that disables us more than it is the actual impairments in our biology. I would say that society is the enemy more than it is the actual disability. If I were to split the issues faced by a person with a disability as belonging to one of two types i.e. medical and political/socio-cultural, in the case of someone living with my type of epilepsy the percentage of issues faced that have been medical in nature have been around the 15% mark and the issues that are political/socio-cultural in nature have made up 85% of all issues faced.

It can therefore be said that living with epilepsy, like other conditions, creates issues borne from a mixture of biology, politics and culture. First of all, let's look at its biology and then the rest of the book will look at the political, sociological and cultural side to living with epilepsy from the perspective of someone who lives with the condition. That person being myself, who is the author of this book.

SO, WHAT IS EPILEPSY?

Everything we think, how we behave, what we say, our perception of time and place, memory, our emotions, our personality etc, is controlled by the electrical activity in our brains. Our brains are made up of brain cells like a brick wall is made of bricks. These brain cells generate the electrical activity responsible for brain function, in the form of electrical waves that repeat themselves. This electrical activity is generated by a simple physiological process involving changes in electrochemical gradients brought on by changes in concentrations of sodium and potassium both inside and outside the brain cells. Let's look at how the brain cell creates the electrical activity that controls your nervous system.

Like a battery each brain cell has a voltage. This voltage is -70mV . In part 1 of the graph below, a substance called sodium enters the brain cells. Sodium has a positive charge and therefore the voltage of the cell increases. At part 2 of the graph, the brain cells' voltage has reached $+30\text{mV}$ and the channels in the brain cell walls that were allowing sodium to enter close; preventing further increases in voltage. Once the sodium channels close, a substance called potassium, which has a positive charge; leaves the cell through potassium ion channels, causing the charge of the brain cell to start to drop. This decrease in voltage is further assisted by a sodium/potassium pump, where three sodium ions (positively charged) are pumped out and two potassium ions (positively charged) are pumped in, resulting in a further net loss of positive charge (Part 3 of graph). This results in the charge of the cell decreasing to below -70mV , to -90mV (Part 4). It is during part 5 of the graph that the sodium/potassium pump, pumps three sodium ions in and two potassium ions out, until the brain cell's charge increases from -90mV back to -70mV where the whole process starts again at part 6 of the graph.



The brain waves that make up the brain's electrical activity are always of the same frequency i.e. number of waves per millisecond, and wavelength i.e. distance between the peaks of each wave; just like a radio station's radio waves are.

What controls the opening and closing of the sodium channels (part 2 to part 3 of graph) are structures called "receptors" that sit to the side of the entrance to the sodium ion channels, opening the channels for sodium to enter at -70mV; and then closing the channels to sodium at +30 mV.

In some people, these sodium channels can from time to time suddenly start opening and shutting much more frequently and for different durations of time than they usually do. This results in the generation of disorganised electrical activity made up of electrical waves of different wavelengths and frequencies. This disorganised electrical activity is what is referred to as a 'seizure', and can last between a few seconds and a few minutes; before returning back to normal. The symptoms one experiences during a seizure is determined by what part of the brain is affected by the distorted electrical activity.

A person who has a "tendency to have recurrent seizures" is diagnosed as having epilepsy. Anyone can have a seizure at any time without having epilepsy. For example, a person in the gym can have a seizure if they lose too much sodium in their sweat, are withdrawing from the effects of alcohol intoxication, sleep deprived, hypoglycaemic (especially in the case of diabetes) or had a stroke. These are just a few examples. These types of seizures are one off seizures, and do not tend to be re-occurring seizures, that can happen at anytime and anyplace; thus meaning that these seizures do not mean that the person affected has epilepsy.

Medications for seizures are called 'anti-convulsants'. Some anti-convulsants act by blocking the sodium channels when they are supposed to close. Other anti-convulsants act on the receptor, thus helping the receptor control the closing and shutting of the sodium channels; preventing them from becoming "disobedient".

It requires a lot of trial and error with many different medications before a combination of medications can be found that control the seizures; however, with perseverance 85% of people with epilepsy do eventually find a combination of anti-convulsants that get the epilepsy under control without having to endure intolerable side effects.

If most people were to be asked about epilepsy it would be a safe assumption to make that all would have a knowledge of the seizure type that causes one to lose consciousness, collapse and undergo violent shaking of head and all four limbs, and experience urinary or faecal incontinence. This seizure is referred to as a “Tonic-Clonic Epileptic seizure”. It would also be a safe assumption to make that the odds of lay people having heard of any of the other seizure types other than “Petit-Mal” are very low. It is unfortunately an ignorance that not only the vast majority of the public possess but also a large number of our public sector workers, and those who work in other service industries where they could come across someone with epilepsy having a seizure on any given day also possess; and this book will highlight the consequences of such ignorance amongst these public sector workers e.g. police, teachers, social workers, public transport workers and other service industry employees such as doormen.

Seizures can be split into one of two categories. One of these categories is called ‘Generalised Seizures’ and the other is called ‘Partial Seizures’. As the names would suggest with ‘Generalised Seizures’, the seizure involves the whole brain; however, with ‘Partial Seizures’, the seizure activity only affects a part of the brain.

There are a number of different types of ‘Generalised Seizure’ as well as there being a number of different types of ‘Partial Seizure’. Let’s have a look at the different types:

Generalised Seizures are: **Tonic-Clonic Seizures, Atonic Seizures, Tonic Seizures, Myoclonic Seizures, Absences.**

Tonic Clonic seizures have already been described and are the stereotypical epileptic seizure. This is the seizure that everyone thinks of when you mention the word “Epilepsy”. It is also referred to as “Grand Mal Epilepsy”.

Atonic seizures are also known as “Drop Attacks” and these are seizures where a person suddenly loses muscle tone and will collapse like a puppet whose strings have been cut. These attacks are only momentary. There is no period of unconsciousness. The person will get back up on their feet but unfortunately because of the nature of the seizure and the environment, injuries to the head and face are very common. These people can often have eye injuries as a consequence of hitting themselves of corners of tables and work surfaces as well as burn injuries. I witnessed a man have one of these seizures on Argyll Street in Glasgow while I was walking to a stationary shop to get some whiteboard pens. This man was crossing a road and suddenly collapsed and got straight back up and kept walking. This man had hit the side of his face off the tarmac while he was crossing a road. You knew it was a seizure as there was no attempt made to break his fall. People affected by this type of seizure should always use the pedestrian lights and would be seriously unwise to ever run across a road giving themselves just enough time to get to the other side.

Tonic Seizures are the opposite of Atonic seizures and they result in a person’s muscles suddenly going stiff causing them to fall backwards. These seizures are also momentary. Injuries to the back of the head are common.

Myoclonic Seizures are seizures that cause the person to suddenly undergo many uncontrollable muscular contractions of their arms and legs. This can also cause them to have falls and injuries. With this seizure there is no loss of consciousness.

Absences are seizures that cause someone to become unresponsive, still and stare blankly with no facial expression for around twenty seconds.

There are also a number of partial seizures. The most common partial seizures types can be categorised as '**Complex Partial Seizures**' and '**Simple Partial Seizures**'.

Complex Partial Seizures are seizures where consciousness is not lost, but consciousness is affected; and the person can behave in a very bizarre way and say very bizarre things. The person is overcome by an overwhelming feeling of anxiety and fear. The person loses awareness and may appear drugged and may start shouting out loud uncontrollably or they may go up to people in the street and start speaking nonsense that does not make any sense. They may also experience loss of familiarity with surroundings as well as anyone they are with, and believe themselves to be elsewhere. There is a period of blackout, that they have no memory of after the seizure, which is the period of the seizure where they say bizarre things and behave in a bizarre way. The blackout is usually followed by a period of confusion that can last for several minutes where they have no knowledge of date, day of week, time of day, anything about themselves e.g. occupation, their plans for today, no memory of yesterday etc. This loss of information can be very distressing and cause a lot of anxiety, as they have no knowledge that they have just had a seizure, nor have any memory of having had previous seizures; therefore, there is no previous experience that they can recollect that will inform them that memory will recover. Gradually over a period of several minutes this essential information that makes up identity, time and place comes back to them. This period of confusion is referred to as the "Post-Ictal State".

Simple Partial Seizures are like complex partial seizures, but as the name would suggest, there is no impairment in consciousness i.e. blackout, nor is there any post-ictal state. In other words, the person will experience the onset of symptoms such as immense fear and anxiety, loss of familiarity with surroundings and those around them, feeling of being elsewhere and then sudden wearing off of the seizure. They could maintain a conversation with you throughout the seizure in theory, but the anxiety and fear may be incredibly difficult to hide from someone they are speaking to. I have had these sitting in coffee shops and pubs and there is no better feeling in the world than the feeling you get when the seizure wears off and you learn that for this time you are not going to have a complex partial seizure. You feel a tremendous feeling of getting away without getting caught.

Complex partial seizures, which is the seizure type that I have, occur in a part of the brain called the 'Temporal Lobe'. There is a temporal lobe on both sides of the brain, and with simple partial seizures only one of the temporal lobes are affected; but with complex partial seizures the seizure activity starts off affecting just one of the temporal lobes, but then spreads into the other temporal lobe, thus affecting both temporal lobes. This is why in complex partial seizures there is an impairment in consciousness but in simple partial seizures there is no impairment in consciousness i.e. no period of loss of awareness, nor period of post-ictal confusion. It is often the case that medication does not have any effect on complex partial seizures, and as a consequence of this; surgery is seen as the only option, which involves the removal of the temporal lobe where the seizure activity begins in. Just like a kidney, a person can live with just one temporal lobe, but removal of a temporal lobe can leave the person with significant memory impairments.

Complex partial seizures can also take place in a part of the brain called the 'Frontal Lobes'. The frontal lobes are responsible for.....