

# EPILEPTOGRAPH THE INTERNAL JOURNEY

*By Isabelle Delmotte*

p2081693@cumulus.csd.unsw.edu.au

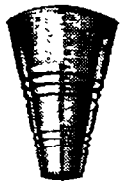
**E**pilepsy is the most common chronic neurological disorder as there are around 40 different known kinds. All forms of Epilepsy are induced by a chemical imbalance, or a structural abnormality in the brain which could be genetic, or caused by physical damage at one stage of someone's life. These impairments can cause electrical malfunctions sparking off uncontrolled and excessive discharges that spread to other parts of the brain, leading to temporal lobe epilepsy seizures. When the whole brain or large parts of it become involved in a raging electrical storm of signals, the result is what is known as a tonic-clonic seizure. Both types of seizures trigger a range of symptoms, such as headaches, nausea, hallucinations, flashbacks, déjà vu, emotional outbursts, lack of awareness, limb jerking and so on. They can make a person hear or see imaginary things, have strange feelings and engage in involuntary actions which often resemble the symptoms of a psychiatric disease. Crude sensations of smell and taste, epigastric sensations, rapid mood swings, chewing movements, lip-smacking, spitting, and other forms of uncoordinated movements are not unusual. As well, tonic-clonic seizures also induce aimless physical wandering, followed by periods of total loss of consciousness, convulsions and amongst other consequences, more or less severe falls. A large number of people diagnosed as epileptics experience some kind of personalised warning sign previous to a seizure known as an "aura". Some don't.

The difference between a temporal lobe epilepsy seizure and the beginning of a tonic clonic one can sometimes be minimal and difficult to notice, even for the person experiencing the seizure. All the sensations experienced in the context of temporal lobe epilepsy seizures can constitute the aura of a tonic clonic seizure. Epileptic fits are not thought to typically leave brain damage but can definitely alter interrelating neuronal connections.

Epileptic activities have a definite physical, emotional and practical impact on the lives of people subject to epilepsy, as well on the lives of those surrounding them. Long term effects include loss of self confidence, loss of trust from other people, personality changes, multiple medication side effects, and so on. There are as many types of seizures as there are individuals living with epilepsy. For each person subject to some epileptic activity, no one seizure is the same as another: mental and physical environments always differ.

The brain as the site of construction and control of consciousness, is the ultimate site of subjectivity. Based on the vari-

isea95@er.uqam.ca T : (514) 990-0229



**ISEA95**  
montréal

ous functions and so-called malfunctions of my brain, "Epileptograph: the internal journey" focuses on the unknown. Regaining consciousness after a tonic-clonic seizure is a visceral and frightening experience which leaves me only glimpses of memory. In the context of this project, the use of the word consciousness could seem a misnomer as this work focuses on the awareness process preceding linguistic ability. Despite feeling the process of life germinating in a chaotic way, the concept of being someone is non-existent. I associate the word consciousness with the ability to articulate emotions and sensations. In my case, having a tonic-clonic seizure means that all memory has been temporally wiped out. Language has to be re-learned in order to communicate with the inner self, as well as the outside world. All sensations and resulting emotions revolve around the absence of language and a time frame. The loss of language implies a loss of time structure and affects all previous references in terms of knowledge. The inability to categorize events in time causes a nearly total loss of specific references. The awareness of the chaos inhabiting the brain triggers a tremendous feeling of fear, which is compounded by the instinctive awareness of a total lack of control. The powerless obedience to the body generates an elusive environment without any time structure. Without the capacity to express to oneself the reality of a situation, Self-awareness is a vacuum of loneliness.

To me this totally non-linguistic event is at once the richest and the most painful of experiences. It is extremely valuable to me as the emergence of all senses triggers the awareness of the unknown self. Beyond words and physical control, the doors of perceptions open to endless primary emotions that the intellect could tend to instinctively denigrate. The process of explaining such primary sensations using words seems impossible, so challenges one's value of language. The apparent limitation of each linguistic unit paradoxically offers infinite potential of understanding based on one's own previous references.

A complex scheme of sensations follows the black-out provoked by the seizure. It involves a slow and frightening reconstruction, done without any words, of any data internal or external to the body. This slow re-accumulating of the self is based on and activated by primal sensations, as there is at all times a physical link between the viscera and the brain activity. It is a process of awareness of procedures and sensations over which the intellect has no control. During this time, the visual and auditory patterns of this chaotic experience map parts of the body, including the brain, with different physical pains and result in a coding system. The body resonates and talks, becoming a very active mass of disconnected layers unable to communicate. Will-power is non-existent as the body has its own agenda. Fear of not reaching a coherent language is instinctive and extremely physical. The progressive recognition of some audio-visual patterns allows language to re-surface, although mental confusion can be present for hours, even for days.

### **On the consequences of the processes**

The actual realisation of this project started in January '92, after 9 years of gestation. To start with, I wrote a text in English named "Epileptograph: the internal journey", aiming to depict my sensations, or absence thereof, during the regaining of consciousness. It is rather ironic that I had to write a text in order to describe this non linguistic episode but as I wanted to depict inexpressible audio-visual sensations, it seemed appropriate to be restrained by a very basic vocabulary. As soon as this process began, it became a constant interrogation of every aspect of language and its social implications. It seemed that every appropriation of a word in order to describe physical sensations could only be done by its juxtaposition to other words. Although this work does not interfere with any medical knowledge, its creation became a metaphor for its subject. While I wanted to describe a loss of language and the struggle to regain it, I was coming across institutional and medical jargons which required some kind of objectivity. The sensations and fears I am trying to describe are not acknowledged by the medical profession or any supportive organisations. According to institutional belief, when someone is lying on the ground during and after a tonic-clonic seizure, this person is not in pain. But emotions are only added to the internal turmoil affecting the physiological body, and are not immobilised. For a witness viewing a tonic-clonic seizure the activity of the 'physical envelop' of the body could be easily connected to an annihilation of the mind due to the brain's uncontrollable electrical activity. The appearance of physical chaos does not always lead to an emotional void. And the term black-out only increases the myth of the physical aspect of an epileptic seizure.

To unwillingly lose control over one's body can be traumatic especially when the point of origin of the loss is a taboo area such as the brain. The most highly valued human organ, the brain in a state of malfunction is feared and reviled. I have been aware of extraordinary mental activity without being able to channel it and articulate it at the time. I have been aware of sensations so intense that language could only translate them as "fears". These chaotic perceptions have made me extremely conscious of the inner turbulences of the body as well as its limits and potential. The brain is as vibrant as a muscle, can hurt as much as bones breaking, can pulse, breathe and pump like the lungs and heart. All physical pains start to emerge after a certain time laps in the process of regaining consciousness, as if a scale of sensations was made out of previous physical referential pain. I consider my brain as a part of my body and every component of my body as a tool of my conscious mind. But in an altered state, each one of these tools has a mind of its own. In an awareness mode, the individual lives and consciousness of these tools are a threat to the sanity of the recovering mind. The primal instinct in the reconstruction of the self is the awareness of the absolute lack of communication tools. The body had a mind and consciousness is a body of awareness ruled by an instinctive language.

## **Intuition as an experiential method of inquiry**

In order to create "Epileptograph: the internal journey", I had to lose control of my thoughts and physical abilities by triggering visual and sonic sensations with the technological tools I have access to. To do so, I relied entirely on my instincts with no idea of the consequences this process would have. Basically I asked my body to remember a state that I couldn't recall but that my body knew better than anyone.

Corporeal intuition, physical emotions and body memories form the core of this project. They are based on the numerous sensations encountered after the black-out provoked by a seizure. I didn't expect this process would provide me with an insight into what is happening during the actual seizure, but in fact it has. So far, my intuition has led me all the way, especially in the use of computer technology as these tools allow me greater flexibility than other methods. They provide me with the freedom of controlling the process only at specific times. Most important is the fact that machines have the power to surprise me, to take me further than physical reality, to provoke me emotionally, to reflect internal processes that I cannot articulate verbally.

It could seem paradoxical to use such a time based medium in order to realise a project which in essence describe the loss of a time reference. To create this loss of time, I wanted to depict the sensation of being in a enclosed space which had its own life and its own rules as this is what I experience on these occasions. The process involved in the creation of the soundtrack has been extremely visceral, therefore highly emotional. I construct sounds completely intuitively as the only criteria for their veracity is their ability to put me in a near epileptic state. As soon as my body is affected by the sounds I become subject to visceral fears, dizziness, sweat, deformed vision, altered sense of time, loss of balance, to name a few of the triggered symptoms. These sensations can be combined or perceived individually. At first I could not believe the impact of these sounds on my body as the resulting symptoms seemed so definite and clear, impossible to alter. It took me 2 years to complete the first 2 minutes of the audio part, the first reason being my inexperience with sounds and the time consuming technics that I developed. The second reason being that I was searching for memories that reside in my body but not in my consciousness. I do not have any recollection of a specific warning sign prior to a tonic-clonic seizure, or at least I do not remember it. But I think there must be one. When I tried to audio-visualise this almost imaginary time frame of a seizure, my body recognised the sounds so well that a near seizure state was a permanent companion in the sound studio. This was my measure of success, to undergo trauma, to retrieve the body memories. I am now able to listen to this part of the sound track with less anxiety, providing that I am in the right emotional state. The process of creating the visuals is similar in the sense that it is totally empirical and completely instinctive.

Two main events have occurred in the past 2 months. First, I was given access to a faster machine than the one I have been using to make the visuals. Consequently, I am not able at this stage to physically absorb the pace of the animated flip books I have been creating: their visual impact generates extreme fears and very painful epigastric sensations. Real time visualisation is too dangerous for the time being. But as the main outcome of this 4 year process has been a therapeutic effect, I should be able to cope with them over the next few years.

I do not know exactly if confronting these fears so graphically has changed my epileptic sensitivity threshold or if it is simply that the process has affected my general perception of my epileptic reality. A mixture of the two is possible as over the past years the number of seizures has decreased and the process of regaining consciousness seems a bit less frightening. Actually it is not less traumatic, but in some ways it seems more familiar. Before I wanted to escape from the experience, now I want to investigate it. Now, on most occasions, I regain linguistic faculties more quickly even if the resulting physical and mental exhaustion can still last for a day or two.

The other main event I would like to mention is a seizure which happened 3 weeks ago. For the first time ever, I was conscious during a 15 mns seizure. The sensations were frightening: life was escaping through my limbs; all sounds were decayed, distant. High pitches were cramping my viscera so painfully that I thought I was going to die. I was literally sucked into a tunnel whose axis was located in the center of these pains. I could not talk, move or breathe properly. I had a poor understanding of my surroundings. Although I was conscious, my mind could not control my body. The most amazing thing was that the visuals I have been creating over the past years were in front of me: I was inside them. The whole experience made me think that the loss of consciousness during all previous epileptic seizures was the natural reaction of my body to prevent this kind of pain. The body has the power to protect the sanity of the intellect by suppressing its connections with of all senses when necessary. The intellect has the power to forget and to anticipate, the body has the power to remember things which will stimulate the mind. Despite all physical pain encountered, this seizure was a major turning point and one of the most positive steps taken over the past 13 years. The feeling of having somehow looped the loop is providing me with a new base. A whole new world of internal questioning and possible understanding is there for me to explore.

Regarding sharing subjectivity, I thought for years that the aim of "Epileptograph: The Internal Journey" was for epileptics, and non-epileptics, to experience the different stages of recovering consciousness as undergone by one individual. Of course, no one will exactly be able to share what I experience, not even myself. What I experience is changing, evolving and my present knowledge of myself has nothing and everything to do with who I was when I started this project. My instincts are

the first public of this work, my body is its interactive viewer, my mind is its virtual space. The few people who have seen this work in progress have expressed physical sensations leading to very different emotions. All these emotions are theirs at the time given, as subjectivity is far from static. What is most essential to me is the process of this work and the resulting chain reaction which goes beyond any expectations. In the future, the product of the process might even become irrelevant for me as it will only reflect a precise time of a previous life. The process itself keeps taking me further internally; its external life only depends on other people's subjectivity. This project has fed me with a multitude of information concerning my own physiological identity and my mental and emotional functioning for the time being and for the time past. It has also given me a broader view of other peoples' internal processes.

The future implications in pursuing the process of "Epileptograph: the internal journey" are limitless as all areas of my life, without any exception, have already been shaken by this work. Being brought back to animal instinct and primary sensations has given me an insight on the physicality of linguistic tools and provided me with another language. The void that words can provoke as well as their power of evocation feed every individual according to their personal history and their sense of future. But having no words does not mean being mute.

© Isabelle Delmotte 1995

*The current realisation of the audio-visual part of this piece is supported and sponsored by:*

- \*the University of New South Wales, College of Fine Arts (Sydney)
- \*the Visual Art/Craft Board of the Australia Council for the Arts.
- \*the Australian Network for Art and Technology.
- \*the Australian Film Commission, new image research program.
- \* Softimage
- \*Glaxo-Wellcome Australia (Imictal division).
- \*Digital Masters (Sydney)

*special thanks to:*

*Char Davies, Jill Scott, Bill Seaman, Adrian Hall, F. & M Delmotte, Fiona Mc Gregor, Mark Williams, Liz King and many many others.*