

# My Experience of Brain Injury: Information on impacts and Recovery

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Having been diagnosed with a large brain tumour at 15, I have decided to write a personal account of my experiences of brain injury and both the positive and negative impacts on my life and the lives of those around me. It begins with my initial diagnosis and follows my path of recovery up to today, 15 years later. It covers the coping strategies I have adopted and adaptations I have made in order to reduce the negative impacts of my brain injury. As part of this, I will cover my experiences both in hospital and at home as well as the various forms of professional, voluntary, charitable and financial support I have sourced and received.

## Initial Diagnosis and Effects

Retrospectively there were several symptoms of my tumour that weren't apparent for some time. I suffered from a lack of physical development and short stature, as well as regular extreme fatigue and fluid imbalance problems. These symptoms were kept under surveillance by teams of specialists both locally and from London for over four years, from around the age of ten. Consequent to this, I was diagnosed with a familial growth and development problem and treatment for this was being discussed by specialists before the acute and severe onset of symptoms. At the time, I was being treated for a lazy eye and new glasses were provided by my optician. Shortly after this, I started suffering from pressure headaches but put this down to my new glasses.

On the day of my admission to hospital, I experienced vomiting, disorientation and acute headaches. Thinking that this was to do with my new glasses, we sought advice from the optician. However, my symptoms got worse whilst at the optician and an ambulance was called. After being rushed by blue light ambulance to my local hospital, my MRI scan results triggered my transfer to Addenbrooke's Hospital, Cambridge. I was diagnosed with a 'Giant Craniopharyngioma' - A benign but serious tumour. Surgery would be imminent, in order to dissect as much of the tumour as was safely possible. Surgery took place within a matter of days, following a short period of investigations and monitoring.

This diagnosis and whole experience was a huge shock to me, my family and friends. After the initial horror, we, with the support of the medical team, all worked through it together. I was very nervous and overwhelmed by the whole sequence of events, the damage that might occur and how I would be after surgery. It was really all about how the tumour had attached itself to surrounding areas of the brain and the risk associated with removing the tumour without causing permanent damage.

## Fears and Concerns

I had never stayed in hospital before and was unsure and anxious of what to expect and about being an inpatient. I was particularly worried about my scheduled surgeries.

Prior to my surgery, my main concern was the potential complications. Although doctors do their utmost to help patients feel at ease, they are cautious to speak of the prospects and outcomes. As a patient you want complete reassurance that everything is going to be fine and you can't really get that.

There are many factors that contributed to my understanding and acceptance that I wasn't alone in my illness and that I was in safe hands. This occurred through interactions with medical staff, learning more about my illness and communicating my concerns. Although this seems obvious now, these pre-surgery worries are both inevitable and understandable. Coming to terms with the realities of my worries and anxieties, I realise now, was just a natural step.

Writing down any questions I had for the doctors meant that I was prepared for any opportunity that arose to calm some of my worries. I found keeping clear and open communication channels with my family was easier using this method. My family were able to stay rational knowing all the facts, which also helped to keep everyone calm.

## **Post-Surgery**

Recovery from surgery of this kind, can take months and years as opposed to days and weeks. My fears have entirely changed in nature as time has passed and further challenges have presented themselves.

The enormity of events didn't hit me until I was home and they became the focus of my attention. Sometimes the immediate physical effects are easy to see, but some of the cognitive effects- such as memory problems and fatigue- are not as obvious. Keeping the focus on addressing problems as they occur is essential for a smooth recovery.

## **Radiotherapy**

I underwent two courses of radiotherapy, in 2002 and 2015. My initial round of radiotherapy was a post-surgical intervention aimed at reducing the solid tumour further as well as preventing any regrowth. Ten years afterwards, components of the tumour caused further problems affecting my mobility, speech and functioning skills. For the three years that followed, I underwent five further surgical interventions to control the areas causing problems. Discussion between treating consultants as to the best course of action followed and a second course of radiotherapy was decided to be the best way forward. I was only the second person with my condition to be offered further radiotherapy. This only enhanced my fear of the proposed treatment and the idea of being a 'test subject'.

The experience caused me a multitude of emotional and physical reactions. My first round of radiotherapy caused my hair to fall out in patches. This was awkward and embarrassing since I was still at school. I had my hair cut very short and my family took to calling me 'Dunlop' as I looked like a tennis ball! The travel to and from Addenbrooke's Hospital was arduous and interrupted the day. I felt bad for inflicting these burdens on my mum too, as she usually accompanied me. On top of everything, the increased and accumulating fatigue only seemed to get worse.

An important lesson I learnt during my courses of radiotherapy and throughout my brain injury treatment, is that every case is different and it is paramount to trust the doctors and not the internet. It was imperative to differentiate between specifics and generalisations.

## **Endocrinology and the After Effects**

Due to my lack of a working pituitary gland, I am now on a cocktail of hormone replacement tablets. As well as this, my fluid intake/output is artificially controlled and I will be on replacement steroids and thyroxin for the rest of my life. In addition, in order to maintain weight control, I have a strict diet and physical movement plan.

## **Organisations and Charities That Have Helped Me**

### **- Headway**

Headway is a national charity providing significant advice and professional support to those affected by brain injury. This support is available to the individual but also extends to family members and /or carers - helping them learn about and adapt to life whilst caring for or living with someone with a brain injury.

My first contact with Headway was with Headway Hertfordshire and a weekly run group called HABIL- Helping Acquired Brain Injury Together - which was led by an Occupational Therapist. All the members of the group had some form of Acquired Brain Injury (ABI). I and the other members of the group were taught a lot of relevant information about brain injury generally as well as specifics. I found this particularly useful as it meant I was better prepared for the subsequent teachings on ways one might adapt to combat the negative impacts. Practicing taught techniques meant I could become far more confident and competent in my abilities. I found that I didn't feel so isolated or self-conscious at these group meetings where everyone was treated with respect in an arena where I could voice my frustrations and feel listened to.

My next and current contact with Headway was with Headway Cambridgeshire. They have not only taught me a lot about the effects of brain injury and strategies to help manage the associated challenges, but enabled me to attend structured sessional groups to help both my physical and cognitive rehabilitation. I moved from Headway Hertfordshire as I felt the facilities at Headway Cambridgeshire were more comprehensive and suitable for my needs. I have learnt this information not only via the teaching of the sessions by staff leading the group but also from sharing information with other clients.

Headway Cambridgeshire has a purpose built gym that has been incredibly beneficial to me. A professional gym instructor supervises and guides every session. My physical stamina along with the positive cognitive benefits, have really helped my recovery and given me a feeling of normality that can be robbed by brain injury.

#### - **Growing People**

Growing People is a small local charity in my home town of Letchworth Garden City, Hertfordshire where horticulture is promoted as a tool to assist people with mental and/or physical disabilities and provides helpful rehabilitation skills. One of the main aims of the charity is to improve the health and overall well-being of the users- known as gardeners- to aid their social inclusion.

Horticulture requires the use of cognitive, social and physical skills. Each individual is given a plot to plant and propagate, growing produce to eventually share and eat with others. I have found that to maximise the efficient use of the plot requires skills in design, planning and organisation.

Being outside is therapeutically rewarding. The calm environment and association with the great outdoors allows me to forget my troubles and truly be myself. The professional staff and excellent volunteers, who support the gardeners, are fun and encouraging.

#### - **Support Network**

Having a brain injury is not something I would ever wish for. It has, however, made me aware of how extremely fortunate I am to have had and continue to have my family by my side throughout the entirety of my 'journey' so far. My family have supported me through unpredictable ups and downs and I feel so grateful and privileged to have their continuing love and support. There is no doubt in my mind that I would not have made anywhere near the progress I have without them. My parents have researched treatment options and agreed the most appropriate treatment plans with my doctors- My mum, in particular, spends a lot of her time ensuring the most appropriate rehabilitation programmes for me and organising/coordinating my outpatient treatment and appointments.

At a time in my life I had expected to be independent, with a career and my own accommodation, I have had to rely on the support of my parents to help care for me and ensure my safety. Due to my blind side, for the moment even safely navigating public transport is tricky for me.

My parents and siblings have been incredibly supportive both physically and mentally. They have given me constant love, care, reassurance and encouragement. I believe they have been the main driving force behind the success of my recovery to date.

I realise that there will be those who might not have family and friends to offer them support when they may need it. However, there are a range of people who patients can talk to within a hospital environment. Not only talking to doctors and nurses when looking for answers or reassurance of a medical nature but to other members of staff on a ward, that one might not have expected to help such as cleaners or catering staff.

## **Key Advice**

### **- Remembering the Journey**

At times, I have found the negative impacts of brain injury can become overwhelming. When this happens, I try to look back at how far I have progressed since I left hospital. This often makes me more optimistic about any hurdles left to overcome.

### **- Accepting Help**

When recovering from the more recent medical intervention, I believe that I have recovered at a faster and better rate than if I had recovered on my own. My sense of guilt that I was burdening those I care about with my problems, especially my family members has abated. I think that I do drive them a bit bonkers with my poor memory and concentration levels by doing things like asking the same questions every day. I am aware I have by no means reached the pinnacle of my recovery. Progressing towards a level of independence means that the help and support of my family will continue to be fundamental.

## **To Conclude...**

Hopefully, my experiences so far can provide an insight into life with a brain injury- From diagnosis to outpatient recovery. A combination of medical, social and charity organisations have given me the support I needed, throughout my recovery.

Most of the support I have needed has come from my family, both when I have been an inpatient and an outpatient, and for this I am very grateful. However, I have also found that there is a lot of support available for those without family or close friends. Organisations often provide support not only to the individual with a brain injury, but also to those providing essential care and/or support.

I have portrayed not only how my brain injury has affected my life, but that if individuals are in need of support there are many organisations both nationally and locally that offer a wide range of activities and services.

My key aims now are to:

- Establish my own family, having the resources and capabilities to care and support them; both financially and otherwise

And to

- Maintain and succeed in a career that satisfies my needs- that is suitably challenging whilst also being considerate of my brain injury and general well-being.

A fact of life is that age brings responsibility for our own health and wellbeing. Personally, this means having to organise and monitor my own healthcare and to utilise all of the help and advice that is offered, in order to be successful in the important things I want to pursue.