

Hi,

My name is Mark Sullivan. I am currently in remission from a malignant brain tumour and would like to share my story with you:

It was November 2013 and I was newly engaged, and planning to marry the love

of my life, Estelle – While celebrating this milestone event with a group of friends

my first symptom occurred. During a general group discussion I made a comment that had no relation whatsoever to the topic at hand! Everyone looked

at me blankly; I continued to babble on. I put it down to my food allergies and thought maybe I had eaten something that didn't agree with me. We headed home and although we thought it was odd we brushed it aside and continued on as normal. Unfortunately, it was the beginning of what would prove to be a very tough and long road ahead and anything other than normal!

This unusual behaviour popped up randomly over the next few weeks, along with some serious fatigue issues. I have always suffered from food allergies; therefore I assumed it was all related to that.

I made an appointment with my GP who also specialised in food allergies. She referred me to an allergy clinic in Melbourne. Basically this clinic injects a variety

of foods and beverages under your skin to see if you have an allergic reaction.

After 3 days at the clinic I headed home with my concoction of all sorts that I would then inject into my body each morning.

I continued this allergy therapy for the next couple of months. Some days I felt it was effective but the majority of time there was no improvement. It was now

a mental thing where I would think I felt better after certain foods although at other times I would have an episode and assume it was due to something I had eaten. I was so mentally caught up in my food allergies that I started cutting out

all different types of foods each day assuming I was reacting to that food. It was

so bad that I got to the stage where I was eating next to nothing but boiled rice,

vegetables and chicken. Due to fatigue I was also surviving on 4 cups of coffee or Red Bull to get me through the day. This had a huge impact on my work as a surveyor and gradually my working hours were getting shorter and shorter.

Suddenly a new symptom appeared - I noticed my short term memory started to deteriorate. I headed to the chemist after work that day and brought some

memory pills. That evening Estelle noticed them on my dresser and asked me what they were for. I told her my memory hadn't been too good. She was shocked and said this was a now cognitive issue. She knew something was seriously wrong and was adamant it had nothing to do with food allergies. She insisted I get a second opinion from another GP.

The next day I headed to this other GP. When asked why I was there I said I wasn't too sure as my memory was that bad and I was so fatigued that I forgot what was wrong with me. The GP then referred me to a psychologist. The doctor

suggested I had posttraumatic depression due to the passing of my older brother

earlier in the year.

When I called Estelle and told her I had been referred to a psychologist she was furious and said there was no way that this was a mental health problem.

Estelle

did a lot of research online. Later that night she turned to me in tears and said my symptoms were showing signs of a brain tumour. This is when she insisted we see yet another GP for a third opinion. Thank God she did or I wouldn't be here today!

The following day Estelle took me to a medical practice in North Sydney where she explained my symptoms to the doctor. He then did a few tests, checked my balance, reflexes, etc., and referred me straight away for an MRI. Estelle called the Hospital and got the first available appointment, which was the following morning.

February 18 2014, we headed to the Hospital for my MRI. It was a horrible experience, to be honest very scary.

The results would take a few hours to go through to the GP; therefore we made

an appointment to see him that afternoon.

While on my way to drop Estelle at work my mobile phone rang. It was a private

number. We automatically assumed it was the doctor calling. We feared the news was not great as we were already booked in to see him that afternoon -

"Mark, I have your MRI results and I would like you to come in and see me ASAP.

They have found a lump in your brain". I will never forget that moment, never.

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We were driving over the harbour bridge when we received the call. Deafening silence followed this. We were both in disbelief and denial.

We headed home, hugged, cried and made the call to let my family know. It was the hardest call I had ever had to make. I was a 30 year old healthy male and my fiancé, 29 - At the happiest stage of our lives. Then you ask the question, why me? What have I done to deserve this? I would never wish this on anyone. We headed to the GP that afternoon to discuss the results. This is when the doctor confirmed I had a brain tumour. The tumour measured 4cm by 4cm and was located in the centre of my brain. This is all he could tell us at this stage. We were booked in to see the neurosurgeon first thing the following morning. I don't remember a lot about that appointment. I remember the surgeon, Dr M Biggs, explaining that it was very serious and that the tumour had caused a huge amount of fluid on my brain, which is called a Hydrocephalus. This would eventually kill me if not treated immediately. He was surprised, considering how critical this was, that I was still standing and able to operate in a quasi-normal fashion. The tumour was located in a very complicated spot, a critical area of the brain that includes the pituitary gland, hypothalamus and optic nerve. The next crucial question; was the tumour benign or malignant? The doctor couldn't give us a definitive answer but looking at what he saw he assumed it was benign. Phew! We made sure we stayed positive and focused on each obstacle as it was thrown at us. I was sent directly to ICU (intensive Care Unit) that afternoon where they would monitor me very closely with surgery scheduled a couple of days later. Prior to ICU I had to do an eye test. Due to the location of the tumour they had to check whether the tumour had caused any loss of vision prior to surgery. I can't remember a lot from this point on, although I remember feeling like I was going to pass out at the eye doctor's and also on my way to ICU. I was monitored very closely that evening at the ICU unit. Things weren't looking great so they decided to bring forward my operation to the following morning as a matter of urgency. I was afraid, very afraid.

19 February 2015 – Operation #1

This was a very critical operation. During the first operation they entered through the top of my skull. I don't remember a lot from this point but do remember waking up after the surgery not really feeling that terrible. That evening Dr Biggs came to Estelle and I and explained that 30% of the tumour

was still there. Dr Biggs explained that due to the location of the tumour they have to be very careful with the removal of the tumour to ensure they did not hit any nerves, as that could be fatal.

They scheduled the next operation for the following day to remove the remaining section of the tumour.

20 February 2015 – Operation #2

Here I was back in theatre for my second lot of surgery, back to back, so to speak!

This time they entered from the side of my face, beginning at the top front part of my skull, down the side of my face and through my jawline. I don't remember

anything really after the second surgery - Everything for the next few weeks was

a blur. There was a long road ahead. Following this second lot of surgery I looked

like I had been beaten up. My face was incredibly swollen, combined with a massive black eye, which I could not open for many weeks to follow. I also had some crazy big staples in my head and a really funky haircut to go with it!

I spent the following few nights being monitored closely in ICU before I was moved to a private room where I would continue to be monitored for some time.

During my time in recovery I experienced a whole range of issues. Due to the location of the tumour it had affected a huge range of functions in my brain, which related to different functions in my body.

We now anxiously waited for the pathology results of the tumour. This took a few more days than usual. Because it was a rare and unusual type of tumour it was sent to several laboratories around the world to seek their scholarship and diagnosis.

A couple of days later the neurosurgeon, Dr M Biggs, called a family meeting. This is where we were informed of the news we dreaded. The tumour (cancer) was malignant! I had now been told, black and white, I had a malignant tumour.

This type of cancer does not yet have a cure via conventional therapy.

My tumour was labelled a high grade III anaplastic astrocytoma. Anaplastic astrocytoma is a WHO grade III type of astrocytoma, which is a type of cancer of

the brain. In the United States, the annual incidence rate for anaplastic astrocytoma is 0.44 per 100,000 persons, making it rare. Anaplastic astrocytoma

fall under the category of high grade gliomas (WHO grade III-IV), which are

pathologically undifferentiated gliomas that carry a poor clinical prognosis. Unlike glioblastomas (WHO grade IV), anaplastic astrocytoma lack vascular proliferation and necrosis on pathologic evaluation. Compared to grade II tumours, anaplastic astrocytoma are more cellular, demonstrate more atypia, and mitoses are seen.

Since having the tumour removed in February my life will never be the same again.

Radiotherapy followed: I would head to hospital 5 times a week for a period of 6 weeks to undergo radiation treatment. It was a horrible experience and very exhausting.

Following on from the surgery my main focus was my rehabilitation. My shortterm

memory was still terrible, pretty much non-existent. I had trouble walking due to my balance being affected. I had a lot of on-going physical damage due to the location of the tumour. I had to work closely with my endocrinologist.

His

job is to restore the normal balance of hormones in a patient's body. Due to the

damage to this area of the brain I need to take replacement drugs for the rest of

my life. Furthermore, there was significant impact on some very critical areas of

my anatomy - I lost my right peripheral vision from both eyes – in other words, I'm blind in the right field of both eyes, therefore I cannot drive. I have also lost my sense of smell - I can no longer smell anything which has its advantages but also its disadvantages. Also, my body cannot regulate its heat anymore, so if I move around a bit I can start to heat up very fast, and it takes a long time to cool

down, my body doesn't register when I am "full", therefore I am constantly hungry, which is very frustrating!

Good News: Estelle stood by me and married me! How fantastic is that! Also, my memory has been greatly restored.

The next step:

I am currently in remission but have been informed by the medical team that the tumour will most likely come back. One thing is that we do not know when - It could be 6 months, 2 years, 5 years or even 20 years, but the likelihood of the tumour returning is high.

After extensive research we have decided to head to Germany to the Duderstadt

Clinic, for a treatment known as Dendritic Cell Immunotherapy for a cure.

This is a real opportunity for a long-term cure and a normal life.

They have had outstanding results with many other patients in my predicament.

Essentially, and using my layman words, the treatment involves taking my blood,

treating it with cutting edge immunology technology and then returning it to my

body for a complete cancer remission.

We are really excited because I can now see a future for us, if I can get the treatment.

The downside of the treatment is that it is expensive and it would mean we would need to relocate to Germany while I received the treatment.

The Duderstadt Clinic cure requires 5 separate treatments. The first treatment is for 12 days, followed by four subsequent treatments, each of two days, separated by one-month intervals. During this time I need to remain nearby.

For the treatment to be successful I will need to do return visits every 4-months for an unknown number of years.

I need \$110,000 to complete this treatment – this includes, the actual treatment

at the clinic, economy airfares and modest accommodation; **unfortunately, it is**

a very large amount of money and I need your help.

My goal is to get to Germany ASAP and ask that you share my story.

Thank you.