

# Presentation by Sally White at the Melbourne Brain Tumour Forum, Sunday 3 March 2013.

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Firstly, can I say thank you Catherine, Denis, and the board for asking me to speak at this event. I am mindful that many of you could have been asked to speak and that my experiences are in some ways likely to be very similar to your own.

I can't possibly speak about my experiences associated with a brain tumour diagnosis without acknowledging my mum, who died from a GBM in 1998 at age 64, only 5 months after her diagnosis. My maternal uncle also died from a GBM in 2009.

I miss my mum and would have liked my children to have known her.

My brain tumour diagnosis came from nowhere it seemed. I was lying on the beach during the day on New Year's Eve when I had a major seizure.

I lost all control and have little memory of events over the next couple of hours.

I distinctly remember being told the results of my MRI, as I'm sure many of you will.

## ***Something has shown up on your MRI scan***

“There is no easy way to say this,” the Doctor sitting in front of me said. “Something has shown up on your MRI scan. You have a brain tumour”.

At the time of my diagnosis in 2007, I was 38 years old, I had been married to David for 14 years, our boys were 11 and 9 years old. I was working full time as a social worker, in addition to doing voluntary work in our local community.

I was diagnosed with a grade 2 oligodendro astrocytoma the size of a small orange.

Suddenly, life as I knew it stopped.

Since then I have had biopsy surgery, awake cranial surgery, a second surgery, and 14 months later, 6 weeks of radiotherapy. Throughout this time I have had multiple MRI scans.

I discovered at my routine November scan that my tumour had started progressing to the extent that further intervention was needed. I am now undertaking 12 months of chemotherapy.

## ***Loss of control profound***

The loss of control I have felt at different times throughout this medical intervention, to varying degrees, has been profound. Waiting for appointments, waiting to go into surgery, waiting for test results and waiting for decisions about my treatment plan, have been a regular feature of my experience.

The most difficult part of the waiting in the early days was not being able to control the thinking that was going around in my head. I was overwhelmed with fear. The physical symptoms associated with that fear, which I carried around with me every minute of every day, were a constant reminder that I was part of the medical world now and I had an illness that I knew had the potential to cut short me life.

After my first surgery, in 2007, I had significant bruising, lost my hair on the right side of my head, had difficulty eating because my jaw was so sore and I had the most debilitating fatigue that I have ever known. Loud noises, conversations, car trips, phone calls, visitors, were all just hard work. Initially, I slept most of the time and I when I was awake I felt like I was in a fog and the world around me was moving very quickly.

### ***"Mum - you look crap"***

The first thing my son, who was 9 at the time, said to me in the hospital was "Mum – you look crap" and when I looked in the mirror for the first time I had to agree with him.

Recover from surgery was slow as I tried to accept my diagnosis and understand what it would mean to find a 'new normal'. I had MRI scans every 3 months and could still see tumour that was left behind after surgery on each of these scans. My Melbourne specialists had recommended no further treatment. It was a case of acting when the tumour grew back. There was never any suggestion that it wouldn't grow back but it might be months or years.

As you can imagine I just wanted it out of my brain. I was desperate to see my children grow up and I wasn't willing to sit around and wait.

I quickly discovered that there appeared to be a gulf between traditional medical practices and complimentary therapies. Nonetheless I started to seek out a range of alternative therapies from around Australia with varying degrees of success. I fell asleep during meditation at first, hated beetroot juice and fell over in yoga many, many times. I made a number of significant changes in my life including meditation, diet and regular exercise.

### ***"We never have white bread"***

It was about 12 months later my son Ben, age 9 at the time, was in the bathroom cleaning his teeth and had a complete meltdown about the toothpaste not coming out. I

knew something was wrong. When I asked him he said  
“Nothing's the same anymore. We never have white bread”.

I suddenly realised not only had my life changed but everyone around me had been affected too. I was not living, I was only surviving. I had been rotating my life around my diagnosis and living in fear about what would happen in the future that I couldn't control. I was busy bargaining for my life, trying to do all the right things in a desperate attempt to stop the tumour growing back. It was time to stop.

I needed to start ‘living’ not just surviving. Ben and I agreed that he would have white bread on the weekends and I had my first glass of red wine the following night.

Since then, my life has changed forever. I am more involved in my treatment planning and our family has learnt that information is power, whether you choose to act on that information or not.

### ***"You get three quotes when renovating a house ..."***

My sister, who is a nurse, said to me “you get three quotes when you're renovating your house, this is far more important than that!” So in May 2008 David and I sought a second opinion from a well respected professional.

We decided, based on the new information we had, that I would have a second surgery to remove more of the tumour and potentially improve my prognosis.

I had a further 14 months medication and symptom free, went back to work and resumed my life as I knew it. I decided to write a book ("Three Quotes From A Plumber: How a second opinion changed the life of a woman with a brain tumour") about my experiences to raise awareness of brain tumours and started public speaking.

When I was told my tumour had started growing back and I would need 6 weeks of radiotherapy I was crushed. It had all started again. I had to tell my boys, tell my family and friends, leave work, manage the treatment and the side effects.

In May 2010, I completed 6 weeks of radiotherapy at the Heidelberg Repatriation Hospital in Heidelberg, which will be familiar to many of you.

Fatigue, seizures, hair loss, lack of taste, memory loss and weakness in my left arm were all side effects of the radiotherapy. Fear was no doubt the most challenging emotion I had at this time. I had lost my belief that I would beat this disease and that I could be the exception.

The ‘What if's’ are endless and it's tempting to let them take control of your life.

I have had a challenging time recognising and grieving over the fact that my families' lives will never be the same. Not only my immediate family but our extended family and close friends too. In the past I have blamed myself for taking away their innocence too, particularly my boys.

My diagnosis could have potentially scared me and therefore immobilizes me for life.

### ***My journey is a balancing act***

I have discovered that my journey is a balancing act. Some days my thoughts tip the scales towards optimism and hope and some days they tip towards fear and sadness. This diagnosis has allowed me to become far more mindful of my life day by day and the thoughts that play out so powerfully for us all.

The news that I needed 12 months chemotherapy in November last year highlights the fact that this is a marathon for me, not a sprint. Just like I have trained for the race in the past, I have started training my mind, body and spirit to allow my body the best chance to heal.

I am reluctant to say this because when I was first diagnosed I read a book that said what I am about to say and I wanted to throw the book across the room. At that point I was angry, scared and resentful of my situation. However it does highlight the path I've taken.

Despite my description of what I have lost, and have suffered, to be honest: This diagnosis has been a gift for me.

### ***A gift wrapped in brown paper***

The gift was wrapped in ugly brown paper which I was initially too afraid to take off... but when I did, I discovered I had gain so much more than just a brain tumour.

- Generosity from family, friends and strangers that I have never known before,
- physical, mental and spiritual awareness that I wouldn't have believed possible,
- courage, joy, happiness, hope and the satisfaction of overcoming my worst fears day by day,
- honesty in my relationships that I never thought I would have the privilege of experiencing.

I have met many inspiring and brave people, specialists, scientist and people just like me who have the experience of a brain tumour diagnosis.

I could list many, many benefits of my experience so far.

In fact, if you had told me soon after my diagnosis that David, my husband, would start a registered charity called **Blackwood 8** that has managed to raise over \$200,000 for brain cancer research, treatment and prevention I'm not sure I would have believed you.

I think most significantly, I have lost my fight to control my future and try to accept anything that comes my way.

I have lost my willingness to just be satisfied with surviving and I have gained a determination to live a life that is fun, content and rewarding.

Finally, I have come to terms with the past and try to only look to my future with my family.