UNTOLD STORIES

AS TOLD BY MEMBERS OF
BRAIN TUMOUR SOCIETY (SINGAPORE)

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BRAIN
TUMOUR
SOCIETY
(SINGAPORE)

LIFE — A DELICATE BALANCING ACT

Ian Wahyu Ananto

A seasoned cyclist, Ian's life was put on the brakes when he encountered not daunting trails and downhill slopes, but a brain tumour discovered right in the middle of a divorce. He recounts how the health setback forced him to relearn the most basic of everyday tasks to regain his footing.

I was diagnosed with a brain tumour (Pilocytic Astrocytoma) at 39 during the height of COVID in 2021. There was little indication or warning, as I was free from any known symptoms such as headaches and blackouts..

As a seasoned cyclist, I loved the adrenaline rush of the sport , and the thrill and satisfaction that comes from taking part in competitions and the like. It was during one of my training rides that experienced double vision out of the blue – right in the middle of the Mandai Mountain Bike trail. As the symptom lasted almost the whole day., I sought help at Sengkang General Hospital's Accident & Emergency (A&E) department,where an immediate CT Scan was ordered, When the radiographer rushed to call for the doctor after he had a look at the test results, I prepared myself for the worst.

Told to stay the night for further observation. The next morning, my attending doctor informed me that an MRI scan was up next,to confirm the diagnosis, as they spotted a ‘shadow’ in the CT brain scan but weren't exactly sure what it was the cause of the double vision was quickly revealed—a 1.5cm brain tumour growth near the spinal cord, which demanded immediate medical attention.

I quickly learnt that a surgical slot had opened up at the National Neuroscience Institute (NNI) @ Tan Tock Seng Hospital (TTSH) the following week, and it took me all but five minutes to agree, not wanting any sudden disruptions which might arise from the chaos of the pandemic.

> I lay beneath the bright white sugical lights, and blacked out from the effects of anaesthesia. It was to be another twelve long hours before I regained consciousness, and learnt that the surgery had progressed smoothly.

The tumour resected was also identified as a low-grade Pilocytic Astrocytoma (PA) — a relatively rare condition which had affected my vision, since it had been growing not far from the optic nerve.

All things considered, the prognosis was not too bad, as I did not require adjunct therapies, such as chemotherapy or radiotherapy.
The same could not be said for my recovery —having your brain open does weird things! Staying for a month-long rehabilitation, I had to learn how to master the most basic everyday activities from scratch — walking, showering and the like.

Eager for a return to normalcy, I focused on pushing myself towards every next milestone which brought me closer to full recovery. The fact that I was also going through divorce proceedings at the same time only strengthened my resolve to get my life back on track – literally and metaphorically, as best as I could.

Thus, I quickly resumed my remote role at work – which I had held before surgery – after heading home from the hospital. Looking back at this rough patch in my life, I was struck by the realization that life is indeed short. – brutal, but perhaps all the more beautiful.Sometimes, all we can do is make the most out of things.

Four years on, I am thankful to be disease-free. While surgical side effects such as balance issues, and even slight visual disturbances linger to this day, though to a much lesser degree than before, I have since learnt to adjust to these “deficits”, and am happy to be able to live to the fullest in both my professional and private capacities.

I have also learnt to reshuffle my priorities by finding meaningful ways to give back, – reaching out to Brain Tumour Society Singapore (BTSS) was one.

Giving of my time and energy as a BTSS volunteer has not only allowed me to pay it forward in any small way that I can, but also imbued me with a brand new sense of pride, purpose and passion. Life, like cycling, is a delicate balancing act, and I am glad to have another chance to keep going the distance, no matter the bumps and bristles on the road ahead

ELAINE'S JOURNEY

Elaine Tok

"Life will not go back to the way it was, but it can still be meaningful and purpose filled."

A life-altering meningioma diagnosis uprooted everything Elaine knew and was used to. She opens up about how facing her fears became the turning point in navigating her recovery journey, and how BTSS became a focal point of support.

I was 36 when I was diagnosed with "Benign Tumour of Meninges" in 2021. Prior to the diagnosis, I experienced daily headaches, and had been taking Panadol[1] daily for more than a month. I also had a very poor appetite, with my weight dropping to just 35kg at one point.

DIAGNOSIS UNVEILED

After a Computed Tomography (CT) scan at the hospital, I was warded immediately with a brain tumour diagnosis. In fact, the neurosurgeon spotted not one, but two brain tumours, and advised surgery to remove them. In addition to suffering from constant headaches, one of the tumours were also affecting my hearing.

I underwent two major brain surgeries, one within a month of the other, spending another month thereafter on occupational therapy and physiotherapy treatment for loss of balance problems. Three months since my hospital discharge, I received another thirty sessions of targeted radiotherapy, to shrink the remaining tumour and reduce the possibility of recurrence.

FINDING STRENGTH AMID CHAOS

Having a brain tumour changed everything—not just my health, but my outlook in life and my notion of what is truly important. It was not just a diagnosis, but a disruption to every part of my life. It brought fear and uncertainty, but also a clarity and resilience I didn't know I had.

One thing I want people to know is that brain tumours aren't always visible. You might look 'fine' on the outside, but are battling fatigue, memory issues, mood changes, or constant anxiety about the future within. That is why awareness and empathy matter so much.

I also want more people to know that early detection can make a huge difference. Persistent headaches, changes in vision or hearing, and balancing issues—don't dismiss them. Trust your instincts, and push for answers if something doesn't feel right.

For me, the turning point came when I stopped asking, “Why me?” and started asking, “What now?” I finally accepted the fact that I couldn’t change what happened, but could choose how to respond. That mindset shift—from victim to survivor, marked the beginning of my healing process.

THE JOURNEY FORWARD

Above all, I’ve learnt the value of support — be it family, friends, medical professionals, or the community (like BTSS), and the importance of giving yourself grace.

In the immediate aftermath of my brain tumour diagnosis, everything just felt uncertain — my health, my future and my very sense of self. Recovery wasn’t just physical; it was emotional and mental too. I had to cope with fatigue, cognitive fog, and a deep sense of vulnerability.

My road to recovery involved surgery, therapy, medication, and countless medical appointments, but just as important were the non-medical steps: learning to rest without guilt, setting boundaries, asking for help, and celebrating progress, no matter how small.

I rebuilt my life piece by piece, supported by loved ones, healthcare teams, and supportive communities like BTSS. I learned to be patient with myself and trust the process.

My greatest struggle in my recovery process is keeping up with the level of energy needed in returning to the workplace, and keeping up with life. I still experience some level of fatigue, which started from the days of radiotherapy sessions. Since then, I am constantly finding ways to manage my energy levels.

TURNING ADVERSITY INTO GROWTH

If this experience taught me anything, it is that life is extremely fragile, but we are incredibly strong. I’ve learned to be present, to appreciate the moments others take for granted, and to be grateful for this journey that I have gone through. I have also discovered the power of community—how sharing your story can be healing, not just for you, but for others, too.

Having gone through this huge health crisis in my life, I have to say that I no longer fret the small things, but rather had a profound mindset shift to focus on being present and making meaningful memories with my family, friends, my work clients and the community.

Long-term wise, my challenges shifted — adjusting to a “new normal,” navigating work and relationships, and managing the fear of recurrence. It remains an ongoing journey.

BTSS IS ...
A lifeline. It's the friend I didn't know I needed—the one who truly understands what I'm going through. In a world that often doesn't see invisible illnesses, BTSS sees me.

This means survival, second chances, and strength I never imagined I had. It means being part of a community that lifts each other up. It means honouring the journey—mine and others, and finding purpose in the pain. Above all, it means hope.

[1] *Panadol: A paracetamol-based painkiller.*

STILL HERE

Martin

A corporate high-flier, Martin's post-retirement plans with his wife were abruptly halted when she was diagnosed with glioblastoma, an aggressive form of brain tumour. He shares how the experience has shaped him to live in the present–and not frantic – moment, amidst life's fleeting nature.

My wife and I had been making plans for retirement throughout the enforced work from home arrangement of COVID.As soon as the Singapore lockdown eased in 2022, it became clear to me that it was time to cap my lawyer's pen and take a proper vacation, after more than three decades of being tied to the Singapore work week, even while on vacation.

Occasionally, someone browsing my holiday photos would notice and ask why I always had my hand behind my back – not knowing I was concealing my phone! As soon as the photo was taken, I went right back to it... with May 2023 set as our jetsetting month, we enjoyed planning and going on long trips, and leisurely visits to family and friends. A year postretirement, we had travelled around Europe on an idyllic trip where I could finally put away my phone, and immerse in the sights and sounds of Norway, Spain and Portugal.

We had spent long weeks on our farm in the Philippines, and in 2024, were planning a longer-term visa to tour Spain, which we both adored, – and explore Northwestern Spain in particular, whose beauty we had discovered on our previous trip.

FROM GLOBETROTTING TO HOSPITAL VISITS

It is said that life is what happens when you are busy making other plans. While en route to Philippines to procure some important travel documents before our Embassy appointment, my wife was suddenly struck by a debilitating headache, which also interfered with her language and speech.

Our initial suspicion was a stroke, but the cause of her symptoms revealed to be a brain tumour. On top of it being glioblastoma - the most aggressive type of brain tumour, our immediate challenge was getting back to Singapore promptly for treatment, as the doctor mentioned that she was too sick to fly. Fortunately, after a period of treatment in Cebu, she was given medical clearance to fly, – albeit after a most frantic and worrisome month, during which we had no idea if recovery was possible.

Thanks to the top-notch medical care in Singapore, she underwent a successful awake craniotomy[1] (a very scary concept!), followed by months of radiotherapy, and chemotherapy sessions which put her on the road to recovery.

Looking back, our biggest challenge was coping with the sudden and drastic change in our plans and expectations – from the excitement of doing up trip itineraries to dream destinations, to having to plan everything around hospital visits – it was a hundred and eighty degree shift to accommodate.

HONOURING THE PRESENT

My biggest takeaway is that the incessant drive forward, looking to future events, and anticipation of things to come, can rob us of our appreciation of the present. Life unfolds in the present, , so we need to take time to appreciate the moment, as tempting as it is to rush ahead – sometimes in the chase of things which may never come to pass. Though we had only one year of the retirement dream, I am truly thankful we got to enjoy that fantastic experience.

Our struggle was also a reminder of the importance of community – we joined BTSS at the suggestion of an oncologist, – and very soon learnt that we are not alone. We found empowerment in reaching out to the vibrant and kindred community of people who not only knew exactly what we are going through, but were also willing to speak up and share their experiences with knowledge, compassion and understanding.

There are also active members who have themselves lost loved ones to brain tumours in years past, but still stay connected to assist others who might be struggling with similar experiences to what they had gone through. One day we will not be here – and this is true for all of us, but I have learnt that while we are, let's enjoy the moments we have, because the future is not ours to know.

[1.] *Awake Craniotomy: A highly specialised surgical procedure where the resection of brain tumours is carried out while the patient is awake for some period of time, to allow for neurological testing.*

COLIN'S JOURNEY

Colin Chee

PRE-DIAGNOSIS

It was months of mystery not knowing why I kept losing my balance veering to the left side as I walked. Visits to GPs, polyclinics, A&E presented theories and suspicion but no clear answers. My hiking stick did not help much and a nasty fall down a flight of stairs left my leg with a nasty bruise. Week after week of travelling on public transport to work and other activities, I began to feel like a burden to the public. "Excuse me, help me, I cannot keep my balance", I often pleaded but most people did not help me.

After two sessions with a physiotherapist, I was advised to arrange for a Brain MRI appointment. Clueless on what possibly went wrong, I made a walk-in MRI appointment at a private clinic, admitted through the A&E department of a government hospital, a Neurosurgeon was assigned to my case and explained that craniotomy had to be done to resect the tumour within a few days. There was concern that the tumour may rupture due to the limited space and pressure on my skull.

SURGERY AND TRAUMA

I had just two days to prepare myself for something I knew nothing about. I was wondering if I would even survive the surgery given my underlying conditions. I survived High Grade Lymphoma during my childhood and Dilated Cardiomyopathy (a form of heart failure) a few years ago but this was going to be an entirely new experience for me.

The surgery on 7 Jan 2022 took 13-14 hours and I was in the OR for 18 hours. When I woke up in the High Dependency ward, I felt like I was in a dream and my vision was blurry with "floating lines and circles". I had also lost my voice due to weakened throat muscles from the surgical process.

In the next few days, I had wild hallucinations. One example was that every night I would fly to another country, discover new trees, invent new things and meet famous TV personalities. When morning came, I would fly back and walk into the back door of my ward and slip right back into the bed. Amazing, right?

My dedicated wife struggled to care for me as I seemed to have changed my personality with all that hallucination and agitation.

There was hardly any discomfort from the surgical wound at the back of my head. loss of voice, ability to eat and drink orally, blurred vision and hallucinations totally distracted me. Was I crying? Yes, over the first week I felt shattered looking at the state I was in. It was going to be a long stay in the hospital and I was clueless about my outlook in life.

Simply depressed. It took at least 10 days before I regained my balance and started to walk slowly. After being warded for 2 weeks, I was further warded for 4 weeks of rehabilitation. The COVID lockdown restricted visitors for a month therefore we had no visitors, not even family members.

During the process of Physiotherapy, Speech Therapy and Occupational Therapy, I struggled with depression. What is this Meningioma that I have? Why was the tumour only partially removed? So many questions and yet my thinking was still slow and shallow. Everyday I would cough out loads of phlegm, using up what I recall 15 boxes of tissues in 21 days. There would also be several dental appointments for me and that left me with six teeth and plans to prepare for a set of dentures.

“Why was I the only one with a brain tumour in my ward?”, I asked myself. The patients around me were mostly suffering from a stroke. The feeling was of loneliness, hopelessness and disabled. I could hardly imagine at that point if I was going to be able to recover and get back to my job and things I used to enjoy.

RECOVERY AND HOPE

After 40 days in hospital and 7 more to go, I regained my voice, could climb up and down stairs, started drinking water and looked forward to having the feeding tube removed before discharge. There were countless things to be thankful for. I could walk, talk and enjoy music that had been part of decades in my life. I had also learned that my brain tumour was a lower grade slow-growing Meningioma.

After 47 days in the hospital, I was finally discharged. It was a fantastic feeling to be home and despite having to survive on a liquid diet for weeks, I was thankful and delighted to be able to consume food through my mouth instead of a tube.

In 4 months of medical leave, I had a packed schedule of Radiotherapy, Speech Therapy as well as being disciplined with my physiotherapy exercises and dietary requirements. A humbling experience to see life going by while others go about their daily lives at work, but it helped me to understand that my focus was on the road to recovery. The challenging part of this journey was that people in my life mostly could not identify with my struggles. Rightfully they moved on with theirs and left me wondering where I belong. Then I recalled a recommendation made by a social worker while I was still warded in hospital.

And so I contacted Brain Tumour Society (Singapore), and made my way to attend their first Support Group Meeting in 2023. There I found a community that could identify with my struggles, while also learning about their own struggles. I made new friends and began to feel that sense of belonging in this community. “BTSS is like my own family”, I said just after a few months of attending their events and meetings. There was so much support that I received but also found myself giving support to others. More than just a patient, I found myself being able to volunteer in this community.

Though recovery required me to face and conquer challenges, I found purpose in serving this community. In Sep 2024, I began work with BTSS as a Well Being Coordinator. While no work is easy and often challenging, I found myself loving this community and having a passion to serve others.

THREAD IN OUR HANDS

Jordan Tan

When doctors found a tumour in the folds of their nine-year-old son Jordan's brain, young parents' He Ruiming and Goh Wei Choon's initial reaction was to shield their child from the truth. Instead they did the opposite, and began their fight together with him.

“At least I lived for nine years.” Jordan uttered those words in the garden at KK Hospital,

In the hospital lobby, we read an inspiring newspaper article about an adult who overcame cancer in her childhood, which filled us with hope—something which we knew we needed plenty of, in the days ahead.

As the fight began, our days blurred together.

Some things I quickly adapted to, like memorising the driving route from home to the hospital and back, reciting every speed bump in my sleep, and even becoming an expert at carrying sick bags filled with vomit.

But other things were far more difficult to get used to. Doctors – whose words carried weight, but never certainty, made decisions an impossible choice. “This treatment might take his sight.” “This one could trigger another cancer, years from now.” “This path may buy him time, or cost him more.”

There were no right answers, only the ones, as parents, we hoped wouldn’t break him. Of course, Jordan had fears of his own, too. He was afraid his friends would forget about him, worried about repeating another year in school—and feared he wouldn’t have much time left.

But Jordan never stopped showing up, packing his Young Scientists magazines for every chemo session, playing Monopoly Deal during chemo drips, and asking if the port in his chest made him part robot.

Laughing more than I thought possible for a boy with cancer.

Like many kids his age, he often asked for more screen time. I could have let him have his way; he might not live to see tomorrow. But I chose to believe he would. So I said no.

Because I wanted to believe he’d win his fight against cancer. I didn’t want him to grow up addicted to his screen, trying to numb the fear and pain with distraction. More importantly, I didn’t want to raise a child we were afraid to say no to.

There were long nights where I kept vigil next to his bed, guilt heavy in my chest. For saying no to him, for not protecting him, for everything that was happening to us. But every morning, we got up again, and that was enough.

The Jordan that has emerged as a survivor is slightly different from the J who was first diagnosed two years ago – stronger, braver. On the last day of his treatment, he decided to shave his head as part of the annual Hair for Hope campaign to help raise funds.

Jordan once said he was thankful he could live for nine years. We recently celebrated his 11th birthday, cancer-free. Life, at least for now, has mostly returned to normal.

So if you're there – in a fluorescent-lit room, with hope fraying like thread in your hands... I just want to say hold on. Sometimes, that thread is stronger than it looks.