

Living through and learning from a brain tumour experience

“Would you mind taking a seat, the doctors are examining your scans. They’d like to come and talk to you.”

Well that was it! Because I was in shock, I was wrapped in a blanket and I’ve never had so much sugar in a cup of tea.

I found myself in a room with three surgeons.

“We’ve found a mass... you have dangerous hydrocephalus... we need to admit you to hospital, so a bed is being arranged.”

There was I thinking I’d just have the tests and go home and see my local neurologist for a follow up. Because of my neuroscience background and several years running the Primary care and Community Neurology Society (P-CNS), I thought I might have multiple sclerosis. But a brain tumour had crossed my mind.

Phoning my wife to tell her “I’m not coming home” was rather tricky, to say the least. But before I got chance, she said: “Can I call you back? I’m just getting the children from school!” To describe my thoughts at that point, would need a few *****s!

Friday, 13th March 2015 is forever etched in my memory. The day of my operation. The operation went well; the hydrocephalus was no longer and although the surgeon couldn’t remove the entire mass, he debulked it, removing sufficient for a biopsy. He also fitted something called a ‘Rickham reservoir’ – a dome-shaped device placed under the scalp with a plastic tube that goes into a ventricle in the brain; the purpose being to minimise any future intracranial pressure.

Fast forward one week. I had recovered from the surgery, passing the occupational therapy and physiotherapy tests, and was back home. But a big question mark hung over my future until my phone rang. It was just as we were leaving the restaurant where we had celebrated our wedding anniversary. It was my surgeon. The news was encouraging. The mass was a slow growing grade 2 pineocytoma. I needn’t return for further surgery and would have an MRI scan in three months. What a relief!

Learning point one

As I live through my brain tumour experience, my first learning point concerns the importance of preparing people for when they leave the security of the high level of care received from a specialist hospital. No matter what type of brain tumour, and in fact, whatever the diagnosis, the sense of isolation once you are back home is not insignificant. I know I’m not alone in such a feeling.

Therefore, I would suggest it would help if a staff member explained - either to a family member or patients themselves - that it’s not unusual to experience feelings of isolation after a stay in hospital, which may in part be due to patients becoming attuned to the relative safety of the hospital environment. Such an explanation may help people cope better once they are home. Plus, it offers an opportunity for patients to consider ways, prior to returning home, to help adapt. I’m sure ideas offered by the hospital staff would be welcomed!

When I got home, the impairment of my immediate recall/short term memory became more apparent. Luckily, with my neurosciences background I rationalised that, given the need for the surgeon to tease apart regions of my brain associated with memory, the neurons would reconnect with practice and time.

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The ‘Bindepeople’ on holiday on Dune du Pilat, France 2018. Left to right: Neil Bindemann, daughter Grace, wife Eleanor and son Arthur



Dr Neil Bindemann

I still remember that hallelujah moment when I was rewarded for such thoughts. I had been out in the garden, and I went to make a cup of coffee. But where was my mug? I’d had it in the garden. I then recalled being in the shed, of all places. And yippee, there the mug was, on the shelf! I can’t tell you how much that lifted my spirits.

I had spent months since the surgery fretting about losing my house keys and my wallet. Every time I left the house.

I constantly checked my pockets, rather urgently. Virtually every time visiting a shop or café or on a train to return home I asked myself: “Have I got my wallet?” Then I would urgently check my pockets, doing the same for my house keys. But I still kept practicing my immediate recall, making mental notes of actions I had taken, hoping to get those neurons rapidly reconnected! So, you see, it was a very significant moment for me, remembering that I’d left an object in a rather obscure place like the garden shed. I believe my level of mental fitness, which I now give presentations about, contributed.

Learning point two

My second learning point is this. If it is known that neurosurgery will impair any aspect of a person’s memory (even just for a short time) and consequently interfere with everyday activities (thus impairing quality of life), they and their partner and/or family need the necessary preparation and support from the healthcare services.

But perhaps my key learning point comes from the most eye opening experience, which in my opinion illustrates why we need primary and community care health services to be far more engaged in neuro-oncology care. It would require them to take such a simple step and it would make such a dramatic difference to so many patients’ and families’ lives, not to mention the potential cost savings from supporting and building a person’s mental fitness.

A few days had gone by since returning home from hospital. I had started back to work. I held the belief (and still do), that my rehabilitation would accelerate by working. That stems, in part, from my father’s attitude of what I term “living through illness”, plus his exceptional psychological skills and desire to support people’s quality of life. I also had a need to work, as I am self-employed.

One morning, during those early weeks, a letter arrived. When I realised it was from the hospital my heart rate suddenly accelerated. I needn't have worried. It was a copy of the discharge letter which the hospital had sent to my general practitioner (GP). I read it and didn't think any more of it.

But the discharge letter started to irk me as I continued to work through my memory deficit, the quality of life impact of my driver's licence being revoked and the accompanying loss of independence - to say nothing of my rather uncertain future. Why had nobody from the healthcare professional team been in touch? The answer to that question, which left me rather aghast, will appear in due course in an article on www.neurodigest.co.uk.

Learning point three

So - getting to my third learning point. When a patient and their family have experienced a trauma like a brain tumour which has been clearly documented in the hospital discharge letter, please, please, please can the powers that be make sure that someone from the local general medical practice or even a developing community neurology service picks up the telephone and calls the patient and family. It doesn't have to be the GP. It could simply

be the practice nurse or a caring receptionist, who calls to say something like: "Hello Mr/Mrs/Ms Xxxxxx. I see you've had a rather difficult time these past few weeks, so we just wanted to give you a call and make sure you're okay. If you do need to talk then we're here to help."

If companies can set up automated telephone systems to try and trap you into enquiring about insurance scams, surely it can't be too difficult for health services to simply place a human being at the end of a telephone call!

Thankfully my mental fitness approach continues to help me through my daily life post-brain tumour diagnosis. And I believe it has contributed - along with my decision in March 2018 to go on the ketogenic diet - to the wonderful news I received this March, which was that my brain tumour has remained stable.

For further information about the work of the Primary care and Community Neurology Society (P-CNS) please see <https://p-cns.org.uk/> or contact Dr Neil Bindemann at neil.bindemann@p-cns.org.uk

An extended version of this article can be read at www.neurodigest.co.uk.

More than specialists: how unique education creates clinical leaders and transforms services

Multiple sclerosis (MS) is a complex progressive and heterogenous neurological disease which can start at any age and affects every person who lives with it in a different way.

The number of people living with MS (prevalence), and numbers of people developing MS (incidence) is increasing, including in children. Whilst the disease was initially identified in the 1830's, the last two decades have seen the most significant advances in understanding of MS in its short history. This has

"This is the best MS course - in fact the best amongst all the educational courses - I have been on."

A wealth of knowledge poured on us with patience and well-paced sessions."

led to increasingly effective and numerous disease-modifying therapies (DMT's), greater understanding of the role of MRI and biomarkers in disease monitoring, better understanding of brain health, lifestyle implications, symptomatic treatments and non-pharmacological treatment. These advances have transformed the lives and aspirations of millions of people with MS worldwide.

Increased understanding of MS, coupled with higher therapeutic aspirations, has led to an exponential increase in complexity. MS teams consisting of consultants, specialist clinicians, neuropharmacists and other allied health professionals are expected to provide cutting edge knowledge and information, optimal services and support, joined up care, and innovative

solutions to local challenges within an NHS operating at maximum capacity and always changing.

It is in response to this challenging environment that MS Academy was formed.

A tried and tested model

Part of Neurology Academy, whose vision is to deliver uniquely practical education to produce specialist clinical leaders and transform local healthcare, MS Academy's variety of bespoke courses follows the hugely successful model established 16 years ago for Parkinson's. Fully funded through pharmaceutical support, the Academy is also endorsed by national charities and UK-wide professional bodies.

Originally intended as a one-off course, four clinical specialists collectively developed the 'MasterClass' as a new kind of educational model which would upskill health care professionals (HCPs) in their clinical knowledge whilst supporting them to enact practical changes to improve service quality and delivery: an educational model that delivered real benefits to people with Parkinson's.

The Parkinson's MasterClass has supported 1,500 clinicians and spurred 75% of attendees to develop their own Parkinson's services locally. Now, with eight MS MasterClasses run over three years, and leadership from educational director Professor Gavin Giovannoni, strategic director Dr David Paling and managing director Sarah Gillett, the MS community is beginning to benefit in the same way.

Outputs and outcomes

Offering three levels of MasterClass: Foundation, Intermediate and Advanced, the Academy also provides Neuropharmacy and specialist palliative care courses. Every course, composed of