

# All In My Head: I Was Diagnosed With One Of The Deadliest Cancers



# Forbes

OurBrainBankBrand Contributor

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*Written by Jessica Morris (An excerpt from her book, All In My Head: A Memoir of Life, Love and Patient Power)*

I was told I'd had a seizure while hiking. I was given a CT scan. I had to lie with my head in a case to immobilize it, then I was gradually moved, electronically, into a donut. It felt suspiciously like a coffin, I thought fleetingly.

When the CT scan was finished I was told, somewhat matter-of-factly, that there was 'something' there and that I would need an MRI, the more powerful imaging using magnetic fields, the next day. I might also need surgery. What?

It took me several days to comprehend the scale of what was happening to me. I think I was in complete shock. A couple of weeks later the job of breaking the bad news to me about my diagnosis was passed to a New York neuro-oncologist.

We were led into a small room. I sat in a large swivel chair, my husband Ed beside me, until the doctor appeared. He leant against the doorway and confirmed my worst fears.



‘The pathology report found that your tumor is a glioblastoma.’

I knew it, I knew it, I knew it, I knew it.

Glioblastoma. The worst of all 120-plus different forms of brain tumor. In a nanosecond, my life had gone from one of smooth, predictable joy to one of unimaginable terror. Glioblastoma.

We asked about clinical trials, new treatments, whether there was anything else I could do to improve my chances. He explained how a lot would depend on my genetic makeup. The hospital where I was initially treated had sent a sample of my tumor to be analyzed, and the results would show if I had any genetic mutations that might suit particular trials. I realized I was now part of the dawn of ‘personalized medicine’.

I felt a sober strength running through me. It wasn’t just a question of whether I could cope with such an extraordinary change in my life. It was a recognition that my relationship with this disease was, fundamentally, down to me. That I alone had this unique version of it, and I alone could choose to take the helm.

Thirteen thousand people are, like me, diagnosed with glioblastoma, or GBM, in the US each year. In a country of 330 million people, that means it is very rare. Five per cent of those newly diagnosed patients are alive five years later. That means it is very deadly. Only 5 per cent of applications for research funding into GBM are successful. That means we’re failing.



Not just failing people like me. We’re failing everybody. Because everyone is affected by cancer. Half of us will experience some form of the disease in our lifetime.

When I think about figures like that 5 per cent, it makes my blood boil. I’m cross about how far away we seem to be from finding a cure for my disease, or even finding the funding that might make finding a cure possible.

We need more resources to crack brain cancer – one of the hardest cancers to treat, but affecting one of the smallest patient groups and therefore too often under the funders’ radar.

We're in a Catch-22 where funders won't fund ideas that have no evidence of potential, but without the funding it's hard to explore potential, let alone secure the evidence.

Power. That's the word I ruminate on every day as I run through my mental checklist: am I doing everything in my power to combat the disease?

Doctors as a rule don't tend to be that focused on the whole person they are treating. That's fine when the treatments they are working on can cure you. But when there's only "standard of care" on offer for GBM – a combination of chemotherapy and radiotherapy that was euphemistically described to me by my doctor as "sub-optimal" and which in fact amounts to a depressing lack of hope that leads you inexorably back to the terrible word "terminal" – then from where I'm sitting that's not enough. We need to feel that there's something for us, something to try, some hope. We want to be part of this medical struggle, not just a passive patient receiving the standard of care.

There's a wealth of evidence out there from the online patient community that isn't captured or used. Because I can access knowledge of treatments, fellow patients and carers, and track my fitness online, I'm managing my health in ways impossible for previous generations. So there's bounty out there, and I want to figure out how to get at it, so we accelerate progress towards cracking brain cancer.

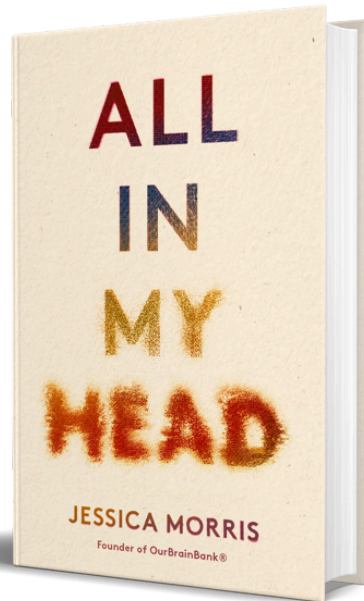
The more I lived with this condition and the more I thought about the funding conundrum that is holding back research, the more I felt that something had to change. Doesn't it make sense to tackle the most complex, most aggressive and rarest type first? Wouldn't that be the quickest and most efficient way to secure better treatments and outcomes for all those with cancer?

It's time to breach the walls between patient and doctor. Let's build a more robust base of evidence drawn from patients' own experiences, and use that as a way to gain insights into what combination of treatments work best. In the process, we might be breaking new ground that could benefit all people with cancer.

We came up first with a great tagline to encapsulate this thinking: "Turning glioblastoma from terminal to treatable, powered by patients". Next we needed a name for the movement we wanted to create. We wanted to reflect that we were a collective force, and that we had a bank of knowledge that could contribute to medical understanding. OurBrainBank was born.

We're making a statement to the world that I, and all my fellow travelers living with GBM, are not 'standard of care'. We are unique souls living on the edge. When we can

rise above the terror, we draw on untapped sources of strength, in ourselves and those around us, and we work to crack this monster together.



*This is an extract of All In My Head, Copyright © Jessica Morris, published by Fleet, An Imprint of Little, Brown Book Group.*

*Jessica Morris was diagnosed with glioblastoma, the most severe of all brain tumors, in 2016. She survived for five years, in which time she battled against the disease with groundbreaking personalized treatment, founded an international charity OurBrainBank dedicated to turning GBM from terminal to treatable, powered by patients, and wrote a book, All In My Head: A Memoir of Life, Love and Patient Power, from which this article is extracted.*

To find out more about OurBrainBank, or to support OBB's work, visit its [website](#). Follow OBB on [Twitter](#) or [LinkedIn](#).



## **OurBrainBank**

OurBrainBank is an innovative, patient-led movement designed to move glioblastoma from terminal to treatable, powered by patients. It's the first non-profit created by, with, and for people living with glioblastoma, an aggressive and rare brain cancer. Founder Jessica Morris (1963-2021) survived for five years after her diagnosis. The five-year survival rate is 5%. We believe in patient power and the importance of donating data to medical research. Patient-driven data is the new currency in medical research. OurBrainBank is a registered nonprofit 501(c)3 based in the US and registered charity in the UK.

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