

Patient Power: The “Normal” Life Of Brain Cancer Survivor DJ Stewart

Forbes

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OurBrainBankBrand Contributor

Apr 3, 2024

By Tess Pilkington

DJ Stewart married his wife Erin five years ago with 31 staples in his head. They had won the wedding in a local radio competition, which DJ had nominated them for from his hospital bed.



Two weeks before the couple exchanged vows, DJ had been signing health insurance papers for a new job when he fell from his desk in the throes of a seizure. He and Erin were new homeowners and had just gotten engaged. Figuring out the ideal place to have the wedding was the only planning they had been able to do.

Before he went in for a craniotomy, they considered holding the ceremony in hospital, unsure whether he would make it out of the ward. The next morning, after a successful operation, DJ got a call back — they were to be married in nine days, at, as it happens, their dream venue.

DJ has never googled glioblastoma (GBM), the brain cancer he was diagnosed with. If he did, he would read that most GBM patients die within 12 to 16 months and that only 5% survive beyond five years of their diagnosis. But he didn't have to, because Erin and his mom took on the burden for him, approaching the daunting task of researching treatment options, learning GBM terms, and translating grueling medical documents with an unwavering strength.

“GBM doesn’t only affect the patient,” he explains to me. “It reaches everyone they love and everyone that loves them back.”

Erin and his mom were just two of an entire brigade behind him, something that not all those living with this disease are fortunate enough to have. He wanted to bring that same sense of community, “the greatest medicine there is”, to GBM patients around the world, and was able to do so thanks to a certain loophole of the 21st century.



After being discharged from the hospital, bearing the indelible mark of 31 stitches across his head, he published his first Instagram post about his brain. Nobody can do this alone, he thought. Nobody.

DJ’s grandma once told him that the day his grandpa was diagnosed with lung cancer was the day he started dying. If subscribing to the diagnosis was one reaction, DJ asked himself, why can’t I do it another way?

He wanted to throw everything but the kitchen sink at the tumor. With the help of his caregivers, the possibilities of treatment options and novel clinical trials became clearer. But when he mentioned to his doctor that he was interested in Optune, the device that beams an electric current at the tumor disrupting its cell replication, he was

met with indifference. “Sometimes doctors or their teams can feel complacent because they think that we’re already dead.”

At this point, DJ, Erin, and his mom were sourcing a significant portion of his own care, reaching out directly to nurse navigators at different hospitals in different states. Accessing his medical files to do so took up a lot of time. “In a GBM patient, time is the most essential thing. And that means we need to have everything at the drop of a hat.” In order to be his biggest advocates, they needed access to his files.

He stops the interview and makes a point of saying: “If you have a question, or a concern when meeting with your doctor, be the loudest in that room.”

The best DJ’s ever felt in a doctor’s office was when he met with a new neuro-oncologist who knew everything about him. He could recite DJ’s medical history up until that point, interweaving skateboarding jokes with the avid skateboarder to lighten the mood.

He even asked DJ about his Instagram page. His attentive interest in DJ made him feel like he was more than a patient, he was a person.

He even minimized the visit to just a short event in DJ's life. "What are you doing the rest of the day?" the neuro-oncologist asked. "What would you be doing if you weren't here right now?"

DJ doesn't stop being himself when he enters the hospital for his regular checkups. Instead of sitting on the patient table, he sits on the corner chair. If the doctor tells him to walk in a straight line, he does it backwards, or he'll moonwalk it, or skip it. When the nurse asks him, "Have you had any falls this week?" he says, "If I go do what I enjoy for fun, skateboarding, I'm falling 30 times."

For those living with this horrible disease, normal life isn't taken for granted. DJ knows he shouldn't be riding motorcycles, yet he's calling in from a motorcycle cafe as we speak.

Perhaps alongside community, normality is the greatest medicine for this disease we have yet to beat.

"They say if you really want to do something next week, you're going to feel better all week."

Amid boundless uncertainty, DJ has plans for tomorrow, for 10 days from now, for next month, next year; for 10 years from now. Because living a "normal" life makes him want to keep living a normal life. He hears "live like you're diagnosed", and responds, "live like you're living."

Tess Pilkington is a member of the board of OurBrainBank, a non-profit which operates in the US and UK. OBB is dedicated to turning GBM from terminal to treatable, powered by patients.

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

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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.

All photos: COURTESY OF DJ STEWART