

I Wish I Could Have Saved Her: The Caregiver's Perspective



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OurBrainBankBrand Contributor

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By Tess Pilkington

“I found out my mom, Karla, had a brain tumor in April 2022, a month after her 50th birthday. The news shattered our world. She was my best friend,” Michelle Robles says before shifting her gaze to her one-month-old son Michael, nestled beside her and her husband David Robles.

David was Michelle’s right-hand person during the nine months from Karla Lara’s diagnosis with glioblastoma (GBM) to her death. GBM is the most virulent form of brain cancer.

It is also the most common, though it is still very rare. About 13,000 people are diagnosed with the disease in the US every year, and barely 5% of them go on to survive beyond five years.



Median life expectancy at diagnosis is a devastating 15 months.

Karla’s tumor was located near her cerebellum, the part of the brain that is responsible for coordination and movement. Within weeks, the disease had robbed her of her independence.

Michelle describes herself during that time as becoming a mini version of her mom caring for her when she was a child. She prepared Karla's meals, helped her shower, took her to all her doctor's appointments, managed her finances, and assisted her with additional activities of daily living.

Even still, she can't avoid the feeling that she didn't do enough. "I wish I could have saved her," she says.



Michelle and Karla took their last mother-daughter trip together to Venice, Italy in 2019 before Karla fell sick with glioblastoma (GBM) brain cancer.

Guilt is a common part of grieving. It's particularly profound among GBM caregivers, however. The basic medical treatment for GBM, known euphemistically as the "standard of care", is less than effective at combating this brutal disease. Caregivers of GBM patients often end up directing frustration at the inadequacy of treatment back at themselves.

What would have been enough? I ask Michelle.

We both wonder: is the standard of treatment for GBM in the US *enough*?

Karla's doctors were reluctant to explore treatment options beyond their hospital's confines. Left to fend for themselves, Michelle and David still couldn't reach out-of-state second opinions due to financial constraints.

Had they done so, they might have been able to explore alternative and experimental treatment options more thoroughly, as well as anticipate Karla's adverse response to the new treatments she was given. She was prescribed Avastin and Carmustine chemotherapy intravenously after the initial round of treatment proved ineffective, and

unfortunately this approach only exacerbated Karla's sickness and further complicated the end of her life.

Michelle and David detected a general lack of compassion from Karla's doctors that left a "sour taste" in their mouths that lingers to this day. They especially felt the absence of a single contact person, a guide, who could have helped steer them through the often bewildering medical journey they were on.

That left them in the at times daunting position of having to be Karla's biggest advocates, because no-one else was there for them.

In the aftermath of Karla's death, David came across a [Bill of Rights](#) co-written by OurBrainBank, a patient-led movement dedicated to moving glioblastoma from terminal to treatable. The Bill of Rights provides caregivers with essential knowledge to advocate for their loved ones during doctor meetings, encouraging them to ask questions, seek second opinions, and prioritize self-care.

David understands first-hand what it's like to go through the GBM mill, and now wants to bring the empowerment that is promised by the Bill of Rights to other brain cancer caregivers. He joined OurBrainBank this year to lead a nationwide survey to demystify the quality of care for GBM patients, and will use the data collected to demand better care for GBM patients and their families.

Michelle experienced her mother's suffering so intensely and so intimately that at times it instilled in her a profound sense of isolation. Who could grasp what she had seen, what she had felt, what she had lost? She feels she will be haunted by the experience forever. "After seeing everything your loved one had to endure, you are never the same person again," she says.

Although Michelle was her mom's primary caregiver, David was her biggest support system. Every time Karla descended the flight of stairs in her building to begin the hour-long journey to her doctor's office, he would carry her.

He witnessed Michelle relentlessly defend her mom's desire to live, and knew to care for her too.

Michelle boils down her advice for other caretakers to one simple thought:

“One of the most important roles you can take as a caregiver is being your loved one's healthcare advocate. No one is going to fight harder for them than you.”

As for the guilt she periodically wrestles with, Michelle focuses on what her mom would want for her in those moments. “Your mom wants you to be happy,” she tells herself. “She wants you to know that she is no longer suffering. She wouldn’t want you to still be stuck in that place.”

Michelle tries to remind herself of that, but it’s hard.

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.

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