

Senator McCain: Living Well Until the End

In our brain-tumor community, each of us spend countless hours wondering what we will do when we receive news of a “bad scan.”

August 26, 2018 By [Adam Hayden](#)

A version of this post also appeared on the [End Well blog](#). The [End Well](#) Symposium, taking place December 6, 2018, in San Francisco, CA, is a “day of learning and connection as we engage with one another, across disciplines, to transform the end of life into a human-centered experience.”

On Monday, August 20, 2018, I held closed the gaping hospital gown with a twisted grip behind my back. I shuffled across the hall from a small dressing room into the radiology suite, set the locker key on a small table, and approached the large, humming MRI machine. The radiology tech draped a warm blanket across me, and she glided my still body on a flat bed into the open mouth of the large magnet. I breathed deep belly breaths for 45 minutes while images of my brain rendered on a computer screen in the booth outside of the room.

For people living with brain cancer, these days punctuate the anxiety of our daily lives. The results of our scans indicate positive response to treatment—the best outcome; stability from the previous scan—the second-best outcome; or disease progression—the worst of possible outcomes.

I have been living with the brain cancer, glioblastoma (GBM), for over two years. A disease many call “the beast.” A disease that one peer reviewed article named “[the terminator](#).”

Many in our brain-tumor community confront the reality of this terrible, life-limiting disease, and each of us spend countless hours wondering what we will do when we receive news of a “bad scan.” These conversations surfaced in our home this week as my wife and I waited for the results from my recent MRI.

While biding our time until our scheduled office visit with my neuro-oncologist to review the MRI images, we heard news from a dear friend facing progression of their disease with no treatment options. They wonder, What now?

Next, in this same week, came news of Senator McCain’s decision to refocus his treatment from

disease-focused to quality-of-life-focused. The McCains wondered, What now?

Then, we heard news of the Senator's death.

Amidst this emotional news—public and private—my wife and I huddled in a small medical office with my neuro-oncologist. He told us my MRI scan was, in fact, “stable,” indicating no evidence of disease progression. We each took a deep breath before scheduling my next MRI and office visit in 12 weeks.

A refrain plays in our minds of words delivered by my oncologist two years earlier during our first office visit with this specialist when we heard my diagnosis: “It is extremely unlikely that you will not have recurrence.”

Translating this “medical speak” into plain language, my doctor was informing us that, despite aggressive brain surgery, my cancer will almost certainly return, or “recur.” GBM infiltrates the nooks and crannies of the brain, and it remains impossible to remove completely by surgery. Resistant to chemotherapy and radiation, GBM grows like tentacles through the soft folds of brain tissue. In short, my wife, family, and I expect to face the difficult question, What now?

The mission at End Well is affirmation: “[A]ll people should experience the end of life in a way that matches their values and goals.” Both dying and living well are inextricably linked. The mission continues, “We are a diverse group of people who listen and learn from each other.”

Today, I reflect on the events of this week. Patients and their loved ones across time zones, including our family, close personal friends, and an American icon, all shared their experiences in public ways to teach and learn from others.

Senator McCain's death came with quiet dignity and expressions of love from this wife and daughter—an alignment of values and goals. This is an opportunity to witness the aims of End Well manifesting in the life and death of a public figure.

How might we learn together in our own homes and in the public arena? In other words, What now? Join us in search of the answer.

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