

# An unambiguous prognosis

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## Correspondence

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### Audio

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I met Mary shortly after she was diagnosed with glioblastoma multiforme at age 54. It was easy to like her; she was stylish, well-spoken, and athletic. Her effortless manner and engaging smile charmed me into nearly mistaking her for an old friend instead of a patient just getting to know her oncologist. Her husband doted on her as he held her purse, fretted with her jacket, and placed his hand gently on her back to guide her into the vinyl examination room seat. His adoring gaze on her was comforting to me. This was a woman who was loved and had someone who would be taking care of her. New patient visits can provoke uneasy feelings in me, knowing that a difficult journey is ahead and that as the doctor I will be the one who cannot meet the patient's hopes for a cure. The average patient will survive only about 14–18 months despite our best efforts, and it can be hard not to consider this as a personal failure.

That day, I learned that Mary had survived a series of seizures and a grueling surgery that had left a raw row of surgical staples tracing her hairline. Her hair had been shaved back a few inches on the left side, making her eyebrow appear raised in alarm, despite her easy smile. Recovery had been rocky following a perioperative intracranial hemorrhage that had weakened her right arm and leg. Recently she had returned home after a rehabilitation stay relearning to walk and care for herself.

Recommended treatment would entail a 6-week course of radiation, chemotherapy, and more physical rehabilitation. Optimistic, even cheerful, she discussed her fears of the radiation side effects, of nausea, of not being able to work as a preschool teacher. She smiled as she talked with me. She was obviously brave in facing such challenges with positivity and strength, but beyond that I knew little about the person she had been before, whose very being was now under siege. She did not want to discuss prognosis. We discussed practical matters.

“She is brave,” her husband affirmed. He looked worried, fidgeting his hands in his lap.

Mary told me she would “beat this thing” and so, together we began the work of treatment. I knew the prognosis too well, but I tried to suspend disbelief, as I must to maintain the hope any patient needs.

Over 2 years and through 8 beautiful New England season changes, she had the usual, and some not so usual, ups and downs through planned treatment; namely fatigue, insomnia, and episodes of hypomania due to steroids, a blood clot in the calf. Her remissions were temporary, punctuated by close calls that repeatedly landed her in the hospital. Her remarkable recoveries might have been called miracles. She sent me a card at one point thanking me and telling me that she felt safe under my care. Such trust in my efforts was uncomfortable to bear, as I had no cure for her.

On her final visit, she wore a hand-knit cap to cover her thinned and patchy hair. Her stylish outfit was far too big now, engulfing her body in the oversized wheelchair. She smiled as always, but only with her lips. The twinkle in her eyes was gone. Her eyes were clear and unblinking though, as she described what had precipitated this urgent visit. She knew that she was more disoriented and unsure why. Everything felt foggy and unreal. She was falling more. Her right leg, weirdly, did not seem to be under her control. Her husband leaned forward on the edge of his chair to add, sotto voce, that she was much worse than she was telling us.

“I am worried.” He looked it.

He was now carrying her everywhere. Even with the pain medication, her headaches were terrible. She hated to ask him for the medication and instead suffered quietly. She didn't want to admit to pain, but he could see it in her eyes.

"She can't remember things. She hasn't eaten in two days."

"I think the tumor is back," she interrupted him, looking directly into my eyes. The fluorescent lighting accentuated her pallor. Sadness and resignation filled the room. The silence felt necessary.

After a bit, the truth had to be acknowledged. "I am sorry to have to tell you that it looks much worse on your MRI."

"I knew that," she nodded. Mary reached to take her husband's hand. He turned his head away, ineffectually hiding his grief.

"We don't have a lot of treatment options at this point. We have been through all the standard approaches already."

"What do you recommend?" he asked.

"There is another chemotherapy, a pill she could take every few weeks that might slow things down. There are side effects though." And it probably will not make much of a difference, I thought.

"How long do you think she has now?" he asked, seemingly unaware that Mary was still in the conversation.

"I don't really know. She has beaten the odds before. I just don't think she has very long this time. We are nearing the end, I am afraid." The original prognosis had passed months ago and she qualified as a long-term survivor. We discussed the pros and cons of a recommendation that is depressingly termed salvage chemotherapy by oncologists. The term accurately reflects decades of frustration with drugs that help very few people once the cancer has returned after more effective standard regimens fail. They accepted the proffered prescription, but emphasized that no decision had actually been made to use it. They wanted to keep their options open. They would think about it. They politely declined an offer to be connected with a local hospice provider.

"Please call me when you decide how you want to proceed. We will support you however you choose." I shook their hands and it broke my heart.

I watched him push her wheelchair away from our clinic, uncertain that I had said and done right things and certain that she was dying. Her composure and ability to reassure her husband was inspiring. She was definitely brave.

Unbeknownst to me or anyone in our office, Mary had registered with the State of Vermont's Death with Dignity program after her diagnosis. As of a report in December 2016, she

was one of the 38 patients to have done so since passage of the Vermont Patient Choice and Control at the End of Life Act in 2013. Our oncology practice is in New Hampshire, but many of our patients are Vermonters whose conditions theoretically might prompt a request for life-ending medication. However, the prescriber must hold a Vermont medical license and the request for such medication must be physically made in Vermont. I am licensed only in New Hampshire.

During our many office visits, we had discussed Mary's prognosis at various times, especially when things had looked ominous due to progression of tumor or development of serious side effects, had reviewed her advanced directives together, and had several detailed conversations about the goals of her care. She never asked about the Death with Dignity option and it is not something I recommend to patients.

The day after that visit, our office received a phone message from her husband informing us that Mary had the Death with Dignity medication at home, prescribed by another provider. He was not sure whether Mary would use it, but they were happy to have the option and were considering their path forward. They wanted to thank everyone in the clinic for their care and support. Our follow-up calls were not answered.

The clinic secretary read her obituary in the local paper and let us know at our weekly team meeting that Mary had died. We discussed that we rarely know what the very end of a life looks like, and how uncomfortable that was for us. I hope that Mary had her family surrounding her and that she and they were at peace.

It made no difference to our team whether she took medication to facilitate her passage, what my professional opinion might have been regarding whether it is ethically or morally appropriate for doctors to prescribe such medication, or what I might have said had she asked about it. It was her life. I found myself unexpectedly comforted that she had taken steps to maintain her autonomy and dignity in the face of her unrelenting disease. I felt proud of her. That feeling came as a complete surprise. I felt an odd closure in that I had done everything I could do for her as her oncologist, and she had done what she needed to do for herself.

For the moment, I am shielded by state law from the kind of self-reflection that would be required should a patient legally request that I participate in his or her own medically facilitated death with dignity. I do not believe that I could prescribe such medication. It feels antithetical to everything my medical career has been since I recited the Hippocratic Oath as a student. On the other hand, though, that my patient had the option available seems to have provided a source of comfort and strength to her in the face of her own mortality, and that is no small thing. And that must give us pause.

## Acknowledgment

I thank the patients and family members whose experiences in aggregate formed this piece.

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