

Brain Available

Category: Palliative and Hospice Care
written by Sarah Liu | September 26, 2024

To my former neuro-oncologist (separated by insurance):

Greetings, again.

What you said when I first became your patient, about the consequences in adult survivors of childhood cancer with secondary tumors, was spot on, and I'm now in palliative care.

Which will come first: present tumor, ischemic stroke, cerebrovascular disease, neurodegeneration, getting hit by a bus?

I have to ask my current neuro-oncologist why my first tumor, fifteen years ago, mushroomed so quickly, what factor caused that growth. It bugs me that radiologists never approximate the number of microbleeds found in all parts of my brain (cerebrum, cerebellum, new one in pons). They just note "foci of susceptibility." I take three anti-epileptic drugs (Lacosamide, Zonisamide, and Klonopin), with intermittent seizures. Reading your work and other articles, I assume my hippocampus has deteriorated, with increasing memory problems, as well as the location of my first tumor, the temporal-parietal lobe.

I continue to take methylphenidate (a central nervous system stimulant) and would have trouble getting out of bed without it. Waning energy, increasing fatigue, less time to focus, though I still retain full function (writing, reading) up to two or three hours, and have a "pen-a-poem-a-day" exchange with a friend to keep the neurons firing. But physically, after a fall last January, I can no longer run. Interesting observation: walking, yoga, any form of exercise is "good for my brain," yet I feel prodromal about five minutes after I stop, requiring rest for fifteen-to-twenty minutes, to equilibrate. I'm fine afterwards, yet without the break, I'll have a seizure or a headache within the hour.

The above is Too Much Unnecessary Information, given as a warning of what you'll get if desired. I want to leave my brain to your lab, requiring documents for the process to go as smoothly as possible.

I'm also wrestling with the problem of staying in California, dying at home with hospice care. The alternative: moving to my cousin and her husband's place in New Hampshire. But they would put me in a care home at some point. Would it still be possible to ship my brain across the country? If I do die at home in Berkeley, and not in a hospital or treatment facility, how much time is needed to keep the brain safe for transportation?

Weird questions, exemplifying my motto: *What does not kill you gives you a morbid sense of humor.*

If you accept my available brain, I know you'll research it well. Thin

slices, please.

Sarah Liu
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