

On Caregiving – Our Story

Ron Brown

It has now been over nine years since I received a terrifying cellphone call from my wife Leslie in which she could hardly speak. She could only get out one or two words before getting “stuck” - and seemed very frightened and confused. I got home quickly and rushed her to the ER. The MRI made it clear: There was an aggressively malignant tumor - a *glioblastoma multiforme* - invading her left temporal lobe, the region of the brain that controls language. And our lives changed forever.

Two major brain surgeries, six weeks of 3D conformal targeted radiation therapy, and three separate and aggressive clinical trials of chemotherapies administered by the amazing people at UCSF’s Brain Tumor Research Center could not ultimately stop the progression of this aggressive tumor. Although she tolerated the aggressive treatments, was otherwise very healthy and active and largely asymptomatic and just continued living life through much of that time, the tumor finally took its toll and Leslie lost her battle on New Year’s Eve of 2011, twenty months after the first symptoms. She passed away quietly at home - in our living room, with a view of our front garden, classical music on, and a fire in the fireplace. She died without fear, anxiety, depression, or pain, and she was by then drug-free. We knew we had done everything we could do. And she was at peace.

That, in short, was our medical story. But it does not speak to what it was like - what we did, how we coped, her courage, her level of understanding of what was happening, our determination to do whatever we could to hold this disease at bay, her willingness to work at staying physically strong, mentally active, in touch with her friends, and to just live life as best she could - all with her incredible sense of humor intact. I have no idea how she handled it all with such courage and grace. But what I would like to share with you here is what, in retrospect, I felt was important in my taking care of her - and myself as well. It was probably the most difficult thing I have ever done - and the most important.

What I saw as important elements of the caregiving:

- 1. Stay Strong. Be Positive.** In order to help her when she needed help, I felt I needed to be as strong as I could be. This was a scary time - but I did not want to appear fearful. I felt I could be the best help if I could avoid being immobilized by what was happening to her - that this was a battle we were engaged in together as we tried to fight this disease. That meant I needed to stay healthy, be rested, be patient, be encouraging, and most of all, be as knowledgeable as I could be so that I could communicate with her how the treatments she was going through were intended to prevent tumor progression. I wanted to convey to her with as much confidence as possible that this approach would be as successful as possible. I needed to be strong and positive for her - and for myself as well.
- 2. Be vigilant.** I watched her like a hawk (even when she thought that was so annoying!). I always wanted to be able to reliably report to her doctors what was happening with her, so I watched her carefully and maintained a fairly detailed record of it all. She was an independent and private person - and I know she did not like being watched all the time, even though she knew it was necessary.

Manage the schedule. I took over monitoring her medications as well as her schedule - including setting out her daily pills. I think that was a big help to her since she just didn’t even have to think about it. And there were times when it became critical, since a change in some medication often required tapering down a dosage before beginning another. And the schedule for her chemo drugs, blood tests, and doctor visits were often dictated as part of the clinical trials.

Be aware of fatigue. Fatigue was such a huge factor through all of this - even though for most of the twenty months she was very active. While the brain is a very efficient organ in healthy adults, when it is compromised - either through disease or trauma, the neural networks are interrupted. So the brain tries to find new neural pathways, and that is not very efficient, consuming more energy - hence is very fatiguing. It is no surprise, I would remind her, that she would be so tired at the end of a day - especially if she had been unusually active or out with friends. And it was no surprise that one of the first signs of that fatigue was how it affected her language abilities. I watched her “energy level” carefully - and was especially vigilant when it waned.

- 3. Become educated** - I became as well versed on this disease and its treatments as I could both so I could communicate with the doctors and nurses with some level of understanding and so that she didn't need to. I searched the many online resources about glioblastomas, possible treatments, and the brain itself. I even learned to read brain MRIs (using downloaded imaging software) - so I could at least follow the interpretations in the radiologist's reports and occasionally ask the right questions. I researched the various chemotherapies that were part of the clinical trials - what they were designed to do to inhibit progression of the tumor as well as what the potential side effects were so I would know what to look for when she was taking the drugs. And I always wanted to be able to explain to her what was happening - without alarming her or overwhelming her with the details.
- 4. Manage communications.** Because in her case her language abilities became increasingly compromised, I became her voice. She could carry on a casual conversation just fine - especially when she was rested and focused, but did not trust herself to always get it right when it was critical. So she looked to me to at least verify what she was trying to say if not speak for her. Outside of office visits, I handled all communications with her doctors and nursing teams, pharmacies, medical insurance, etc.. Her language skills deteriorated more as the tumor progressed into the second year - and that made my role even more important in communicating with her docs and even with her. But the language deficit was always expressive, an inability to retrieve words, and not cognitive. She always understood what was being said - and what was happening to her.
- 5. Make time for “normal”.** As much as we could, we tried to live a normal life. We went shopping together, made decisions together, went out with friends, and talked a lot. Walking was an important part of her routine - and she walked with one of her best friends several times a week (or with me when she wasn't available!). A frequent weekend activity for us was to walk local trails in San Luis Obispo and then go out to lunch and maybe shopping when we were at home. Or when we were in San Francisco for treatments, we would walk from our hotel in the marina district to Crissy Field and the Warming Hut. She looked forward to those five mile walks - as did I. She liked pushing herself and it gave us a lot of time together. She was a quilter - and her Wednesdays were sewing days which she spent religiously with her quilting group, either at their homes or ours - and that was very important to her (and me as well, as I knew she was with her friends and having fun). We turned the biweekly trips to San Francisco for treatments and doctor visits into three-day vacations. Even the drives themselves were part of that as it gave us lots of car time to talk and just have that time together. All of those things were important to us both. As she became more compromised in those last few months, the walks and shopping trips were often replaced by just driving into town for lunch - sometimes something simple, so she wouldn't need to leave the car.

She was concerned that I was not doing enough for myself. I like to hike and play golf - and she would insist that I go play or practice (“Don't you have someplace you could be?”, she would say.) Because that also gave her some time to herself, as well. It was only in the last three months that it was clear that I could not be away for that much time. And even then she worried that I was spending too much time at home caring for her.

6. Keep a journal. In addition to the detailed medical log that I maintained, I kept an electronic journal. I began right after that first trip to the ER and her first MRI. I wanted to be sure that I had careful notes that I could rely on when talking with any of her doctors or nurses. But the journal became much more important than just a chronological medical history as my entries grew to include what we were doing in addition to how she felt, what we were thinking, what I was learning from my own reading, what we talked about, questions (and the answers) I had for the docs, and what we were feeling about how it was going, and our interpretations of what was happening at the time. It is now a permanent record of that twenty-month journey together.

I continued with the journal for year and a half or so after her passing - an important part of my dealing with my new life without her, recalling things we had done, noting various anniversaries of events, writing my feelings and thoughts and what I was doing to “recover”, if that is the right word.

And that journal has now become a book, “Leslie’s Journey”, a story of how she dealt with it all with such courage and grace. The writing was therapeutic and helped put things in perspective.

7. Remember the good times. I created a photo collection of the good times. One of the things I did that in retrospect was good therapy for me was to assemble photos from our summer travels over the previous dozen years or so - all showing this vibrant, healthy woman hiking in the Canadian Rockies or Utah’s Canyonlands or the Grand Tetons or North Cascades as well as photos of her with friends and in her other activities. The project started during her last summer - while she was still very active and feeling well, but after it was clear that there was tumor progression and that this disease was ultimately going to take it’s toll. I just wanted to remind myself of some of the spectacular things we had done together. It then grew to include images from our earlier years together - in college, as young marrieds, her as a young mother, etc. It shows who she was - and even photos taken in her last few months show her incredible spirit. That photo montage is now a cherished collection of our lives together. Putting it together was good therapy for me - as well as having it now. It is a continual reminder to me of who she was.

I miss so much about her - her laugh and making her laugh, her intelligence, her sense of humor and of whimsy, her wit (in every meaning of the word), and her insights and logic and touch of cynicism - and, of course, our conversations. But I have also missed just taking care of her and making her comfortable - keeping the world at bay and protecting her from worry. I have missed having that sense of purpose that comes with the caregiving - and that is a powerful experience. And I did not expect that. We were married over 43 years, but I don’t think we were ever closer than during those last two.

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“On Caregiving - Our Story”: Can be read online at: <http://www.calpoly.edu/~rbrown/Caregiving.pdf>

“Leslie’s Journey” A story of how she dealt with it all with such strength and courage and grace.
It can be read online at: <http://www.calpoly.edu/~rbrown/JOURNEY.pdf>

“Five Years” Reflecting on the last five years since she lost her battle with cancer - how I’ve continued with life without her. <http://www.calpoly.edu/~rbrown/FiveYears.pdf>

Ron Brown Email: rbrown@calpoly.edu